

Thesis for doctoral degree (Ph.D.)
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LIVING WITH IRRITABLE BOWEL SYNDROME

A patient perspective on everyday life, health care encounters
and patient education



Cecilia Håkanson



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From THE DEPARTMENT OF NEUROBIOLOGY,
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ABSTRACT

Irritable bowel syndrome (IBS) is a chronic functional bowel disease. Adults with IBS represent a large group of health care seekers. Previous research has shown that these people often feel insufficiently informed about their condition, and find it hard to manage the disease in everyday life. The patient perspective on IBS has previously been given limited research attention. **The overall aim** of this thesis was to gain enhanced knowledge and understanding about the lived experience of IBS in relation to everyday life and health care encounters, and to study the influence of a group-based IBS patient education program on the everyday lives of people with this condition. **Methods:** Study I used a descriptive phenomenological method to analyze nine individually-performed interviews about the lived experience of IBS. Studies II and IV were guided by the interpretive description approach. In study II, the participants from study I were interviewed a second time but with a focus on health care encounters. In study IV seven focus group interviews performed with a total of 31 individuals who had completed the patient education program, were analyzed. In study III, which used an evaluative research design, quantitatively-treated data were collected from self-assessment questionnaires completed by 51 individuals before and after the education program. **Findings:** The experience of living with IBS (study I) was described as a struggle with an everyday life that had become obstructed, as the lived body had become unfamiliar and unreliable. Feelings of not being able to trust one's body, of being ashamed of one's bodily symptoms, and of feeling different, appeared to be important contributors to the limitations experienced in everyday life. At the same time, the study participants showed a strong will to exceed these limitations. The most common meaning of being a person with IBS in the patient position (study II) was being exposed to unsupportive health care encounters that were shaped by humiliation, insignificance, and abandonment. Feeling mistrusted, and not being acknowledged as an experienced person, brought a lack of self-trust and a devaluation of one-self. Supportive encounters that were characterized by openness and acknowledgement of the patient's life world were less prominent. In study III, the participants reported differences in their use of coping strategies and scored their symptoms as being significantly less severe after participating in the education program. Study IV revealed the importance of combining reciprocal sharing of the group members' experience-based knowledge with the provision of professional scientific knowledge. Together, these two types of knowledge seemed to have enabled a growing readiness based on new understandings of the body, on seeing illness as part of a whole, and on a new ability to make knowledge-based decisions about strategies to employ in everyday life. **Conclusion:** The experience of living with IBS is in many ways dependent on the fluctuating nature of the condition, and the socially unacceptable and troublesome symptoms related to the disease. The nature and attunement of encounters between people with IBS and health care professionals can influence the existential understanding of a person with IBS, and his or her experience of illness, in a way that either boosts or obstructs the feeling of homelikeness in life. The group setting, as an environment that facilitates recognition and sharing of illness experiences, and as a place characterized by safety and intersubjectivity, is assumed to be an important prerequisite for people with IBS in enabling them to learn to live with the disease; and as such, the concepts of community and mutual experiences become central to the education program.

Keywords: coping; health care relationships; illness experience; irritable bowel syndrome; learning; life world; lived body; patient education; patient perspective; shame; unhomelikeness

LIST OF PUBLICATIONS

- I. Håkanson C, Nyhlin H, Sahlberg-Blom E and Ternestedt BM.
Struggling with an unfamiliar and unreliable body. The experience of irritable bowel syndrome. *Journal of Nursing and Health Care of Chronic Illness* 2009; 1(1):29-38.
- II. Håkanson C, Sahlberg-Blom E and Ternestedt BM.
Being in the patient position. Experiences of health care among people with irritable bowel syndrome. *Qualitative Health Research* 2010; 8(20): 116-1127.
- III. Håkanson C, Ternestedt BM, Sahlberg-Blom E and Nyhlin H.
Learning to live with irritable bowel syndrome. The influence of a group-based patient education program on people's ability to manage illness in everyday life. *Resubmitted*.
- IV. Håkanson C, Nyhlin H, Sahlberg-Blom E and Ternestedt BM.
Learning to live with irritable bowel syndrome. Experiences of a group-based patient education program. *Submitted*.

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POPULÄRVETENSKAPLIG SAMMANFATTNING

Att leva med irritable bowel syndrome. Ett patientperspektiv på vardag, hälso- och sjukvård och patientutbildning

BAKGRUND

Den här avhandlingen tar sin utgångspunkt i ett patientperspektiv. Med begreppet patient avses personer med irritable bowel syndrome (IBS), som var och en har sin unika erfarenhet av hälsa, sjukdom och vardag, och som på något sätt står i kontakt med hälso- och sjukvården med anledning av sina IBS-problem. För att förstå så mycket som möjligt av den situation personer med IBS befinner sig i, är det biomedicinska perspektivet, det som handlar om sjukdomssymtom, utredning och behandling viktigt, liksom kunskapen om människors levda erfarenheter. Ett livsvärldsperspektiv hjälper oss att förstå innebörden av att leva med en kronisk sjukdom som IBS i vardagen, något som har stor betydelse för att hälso- och sjukvården ska kunna ge det stöd som behövs för att främja hälsa och välbefinnande.

IBS eller ”irritable kolon” som sjukdomen ibland också kallas, innebär en kronisk funktionsstörning i tarmen. De symtom som drabbar individen är förändrade avföringsvanor och samtidig smärta eller obehag i form av gasbildning, diarré eller förstoppning, alternativt en kombination av bägge. Andra vanliga problem är uppkördhet, avföringsträngningar, känsla av ofullständig tarmtömning, tidig mättnadskänsla, och ibland illamående. Diagnosen IBS är symtombaserad. Beroende på vilka diagnoskriterier och datainsamlingsmetoder som använts, beräknas mellan 3-25% den vuxna befolkningen i världen leva med IBS. I Sverige har förekomsten uppskattats till drygt 10%. Sjukdomen är mer än dubbelt så vanlig hos kvinnor men varför är inte känt.

Personer med IBS utgör mellan en femtedel upp till hälften av alla patienter i den medicinska mag-tarm- sjukvården och en dryg tiondel i primärvården. Orsaken till att vissa människor drabbas av IBS är fortfarande osäker men enligt litteraturen beskrivs sjukdomen ofta som ett samspel mellan psykosociala och biologiska faktorer, till exempel genetisk och social ärftlighet, störd tarmmotorik, hyperkänslighet i tarmslemhinnan eller sviter efter en akut tarminfektion. I brist på bot inriktas de behandlingsalternativ som finns mot att lindra symtomen. Läkemedel, kost- och livsstilsråd, hypnosbehandling och kognitiv beteendeterapi är några exempel.

När avhandlingsarbetet påbörjades 2006, fanns ett fåtal publicerade artiklar som baserade sig på studier om personers erfarenheter av att leva med IBS. Under senare år har emellertid en gradvis ökning av antalet sådana studier kunnat ses. Sammantaget visar tidigare forskning att IBS är en sjukdom man inte gärna talar om med andra. De symtom som drabbar individen upplevs genanta och begränsande i vardagen. Det upplevs vara svårt att hitta strategier för att minska de problem som sjukdomen medför. Det förekommer också beskrivningar av att personer med IBS känner skuld över föreställningen om att de själva har orsakat sjukdomen, till exempel genom dåliga matvanor eller ett alltför stressigt leverne.

En person med IBS kan ha mer eller mindre regelbundna kontakter med sjukvården. Dessa kontakter kan involvera specialistvård såväl som primärvård. Även om utvecklingen går mot en mer team baserad vård där flera olika yrkesprofessioner är engagerade, är fortfarande läkaren den vanligaste vårdgivaren. Precis som för de flesta andra kroniska sjukdomar, vilar uppgiften att hantera det dagliga livet med IBS, på personerna själva. Kontakterna med hälso- och sjukvården blir därför mycket viktiga för att individen ska få möjlighet att samtala om sin situation, få ökad kunskap om sjukdomen och

råd och stöd i hur det egna välbefinnandet ska kunna främjas. I litteraturen betonas individens upplevelser av sjukdomen, och hur den påverkar livssituationen, som en viktig utgångspunkt i mötet med hälso- och sjukvården. Det har i tidigare studier beskrivits att personer med IBS känner sig illa bemötta och att de upplever att de får brisfällig information om sjukdomen, och därmed inte får det stöd de behöver i att hantera sin vardag med sjukdomen.

Många personer med IBS upplever att de inte har tillräckligt med kunskap om sjukdomen för att kunna påverka sin egen hälsa och sin livssituation. Ett sätt att möjliggöra för människor att få ökad kunskap är genom organiserad patientutbildning. I den litteratur som beskriver forskning om patientutbildning för personer med IBS, förekommer allt från interventioner med enbart skriftlig information, till omfattande utbildningsprogram. Resultaten av dessa interventioner har visat positiva förändringar hos de personer som deltagit, i form av ökad sjukdomsrelaterad kunskap, hälsofrämjande livsstil (kost, motion, stresshantering), minskade fysiska besvär, minskad psykologisk stress och förbättrad livskvalitet.

Avhandlingens teoretiska utgångspunkter

Vårdvetenskap har en humanvetenskaplig grund. Ett vårdvetenskapligt perspektiv utgår från människors egna upplevelser av sin hälsa och förståelse av vård. Patienten betraktas som en unik individ och som den verkliga experten på sitt lidande, sin hälsa och sin livssituation. En central utgångspunkt i avhandlingen är att lära av personers subjektiva upplevelser av att leva med sjukdomen IBS, det vill säga deras livsvärld. *Livsvärlden* har sitt ursprung i fenomenologin, en filosofisk riktning, och beskrivs som den värld, i vilken vi som människor lever vårt dagliga liv, upplever, talar om och tar för given i våra aktiviteter. Kroppen beskrivs inom fenomenologin som en *levd kropp*; en enhet av kropp, själ och värld. Kroppen är navet i existensen. Det är genom den levda kroppen vi finns till och skapar mening i tillvaron. Vi har alltså inte bara en kropp, vi *är* vår kropp. När vi drabbas av sjukdom och kroppen inte längre fungerar som den brukar, uppmärksammas vi på olika delar och funktioner av kroppen som tidigare tagits för givna. Varje förändring av kroppen medför en förändrad tillgång till världen och livet. Det är först när kroppen inte fungerar som den brukar, som den blir märkbar på ett särskilt sätt och upplevs främmande. Ett sätt att beskriva detta kan vara att säga att sjukdom skapar en känsla av hemlöshet i tillvaron. En central fråga i vårdmötet blir således att hjälpa individen att återskapa känslan av hemmastaddhet i tillvaron.

I avhandlingen har ett perspektiv på lärande antagits, som utgår från personers livsvärld, och från grundtanken att varje människa alltid är en del av ett sociokulturellt sammanhang och därmed alltid står i relation till andra människor. Lärandet startar alltid med en erfarenhet. Erfarenheter skapas i mellanområdet mellan oss själva och den yttre världen. Lärandet uppstår när dessa två står i ett slags spänningsförhållande till varandra och ett tillstånd av obalans upplevs, exempelvis i samband med sjukdom, då tidigare erfarenheter inte längre räcker till för att skapa mening i den nya situationen. Strävan efter att uppnå balans anses vara själva drivkraften för människors lärande. När en ny erfarenhet prövas, kan den omvandlas till ny kunskap, med vilken mening kan skapas och balans återfås i tillvaron.

MOTIV FÖR AVHANDLINGEN

Den tidigare beskrivna forskning som tar sin utgångspunkt i människors erfarenheter av att leva med IBS, har framförallt beskrivit upplevelser av symtom, behandling och förmågan

att hitta strategier för att lindra sjukdomssymtom. Det finns således ett behov av att komplettera med studier som belyser innebörden av att leva med sjukdomen utifrån ett mer existentiellt perspektiv. Det behövs också studier som fördjupar förståelsen för vad det kan innebära att vara i rollen som patient med IBS, i mötet med hälso- och sjukvården. De studier som genomförts för att studera patientutbildning för personer med IBS har i huvudsak varit inriktade på att mäta effekter ur ett biomedicinskt eller beteendevetenskapligt perspektiv, och ger viktig information. Det behövs dock studier som belyser vilken betydelse de personer som deltagit i patientutbildning upplever att det haft för deras vardag med sjukdomen.

SYFTE

Avhandlingens övergripande syfte är att få ökad kunskap och en fördjupad förståelse för innebörden av att leva med IBS i vardagen och i mötet med hälso- och sjukvården, och att studera betydelsen av att delta i en gruppbaserad patientutbildning för personer med IBS för individers vardag med sjukdomen. Avhandlingens fyra delstudier har följande specifika syften:

- I. Att beskriva innebörden av fenomenet att leva med IBS ur ett livsvärldsperspektiv
- II. Att fördjupa förståelsen för hur det är att vara en person med IBS att vara patient i av mötet med hälso- och sjukvården
- III. Att studera vilken betydelse gruppbaserad patientutbildning för personer med IBS har för individers förmåga att hantera sjukdomen i vardagen
- IV. Att studera personers erfarenheter av att delta i en tvärprofessionell gruppbaserad patientutbildning om IBS och betydelsen av utbildningen för deras dagliga liv

STUDIERNAS GENOMFÖRANDE

Delstudie I genomfördes med en beskrivande fenomenologisk metod. Nio personer som haft diagnosen IBS under en längre tid (> 3 år) inkluderades från en väntelista till en gruppbaserad patientutbildning, på en specialistvårdsklinik vid ett mindre svenskt sjukhus. För att fånga en aktiv period i livet när det gäller utbildning, yrkesliv, familjeliv och sociala aktiviteter, valdes personer i åldersintervallet 25-60 år. Datainsamling skedde genom djupintervjuer där personerna ombads att så konkret som möjligt berätta om sina erfarenheter av att leva med sjukdomen i vardagen.

Delstudie II är en fortsättning på delstudie I, vilket innebär att samma personer intervjuades vid ytterligare ett tillfälle, men med annat fokus. Intervjuerna inleddes med att personerna ombads berätta om sina erfarenheter av möten med hälso- och sjukvården i relation till IBS. Uppföljande frågor ställdes för att fördjupa och förtydliga deras berättelser och för att täcka de områden som var av särskilt intresse för studien; erfarenheter av hälso- och sjukvårdspersonalens förhållningssätt och kunskap om sjukdomen, erfarenheter av information och stöd i frågor om egenvård samt betydelsen av att få en diagnos. Analys av data genomfördes med tolkande beskrivning.

I *delstudie III* deltog 51 personer som inkluderats från den i delstudie I tidigare nämnda väntelistan. Inklusionskriterierna var liksom i studie I och II, långvarig IBS-problematik (> 3 år) samt diagnos enligt de så kallade Rom-II kriterierna. Personer som stod under psykiatrisk/psykologisk behandling inkluderades inte. En utvärderande

forskningsdesign valdes, där personerna skattade symtomintensitet och användandet av olika copingstrategier före, och 2-4 månader efter att de deltagit i patientutbildningen.

Delstudie IV är kopplad till delstudie III, vilket innebär att samtliga personer, vid inklusionstillfället, inbjöds att delta både i självskattningsstudien och i den aktuella intervju studien. Totalt deltog 31 personer i 7 fokusgruppsintervjuer. Intervjuerna inleddes med en öppen fråga där gruppen uppmanades att berätta om sina erfarenheter från patientutbildningen. Uppföljande frågor ställdes om patientutbildningens innehåll och utformning, om hur det upplevdes att vara i en grupp med andra samt vilken betydelse patientutbildningen haft för personernas vardag. Data analyserades med tolkande beskrivning.

Den studerade patientutbildningen

Den studerade patientutbildningen utvecklades för drygt tio år sedan och har sedan dess varit en etablerad del av verksamheten på det aktuella sjukhuset. Utbildningen bygger på idén att professionell och erfarenhetsbaserad kunskap i kombination ska stärka personers förmåga att öka hälsa och välbefinnande, och därmed minska sjukdomens inflytande över vardagen. Möjligheten att dela erfarenheter med andra i liknande situation betonas. Utbildningen omfattar fem på varandra följande dagar. Kvinnor och män träffas i blandade grupper om 12-15 deltagare. Några veckor innan patientutbildningen startar, träffar varje deltagare en sjuksköterska med lång erfarenhet av att arbeta med personer som har IBS, för ett enskilt samtal. Under samtalet informerar sjuksköterskan om patientutbildningen. Personen inbjuds att berätta om sin egen situation och sina erfarenheter av att leva med sjukdomen. Tankar om att vara i en grupp med andra personer med liknande besvär diskuteras också. Under patientutbildningen deltar samma sjuksköterska som samordnare. Sjuksköterskan fyller också en viktig funktion genom att finnas tillgänglig för frågor och praktiska spörsmål, och genom att aktivt uppmuntra till interaktion mellan gruppdeltagarna. Under den vecka som patientutbildningen pågår, varvas föreläsningar med diskussioner och praktiska övningar. Under veckan deltar följande yrkesgrupper som föreläsare: dietist, läkare med specialistkompetens i medicinska mag-tarmsjukdomar, narkosläkare, psykolog, sjukgymnast, diakon samt sjuksköterska med särskild kunskap runt tarmtömningsproblematik.

RESULTAT

I *studie I* framkom att IBS förändrade personernas livsvärld på olika sätt. Sex nyckelteman framträdde vid analys av materialet; att ha en förändrad självbild; att skämmas; att inte kunna lita på sin kropp, att känna sig trött; att skuldbelägga sig själv; att hitta lösningar. Dessa teman syntetiserades till en övergripande struktur: *Att leva med IBS innebär att kämpa med en kropp som känns främmande och opålitlig. Trötthet, att inte kunna känna tillit till, och att skämmas över sin kropp, medför begränsningar i vardagen. På samma gång innebär att leva med IBS att ha en stark vilja att överskrida begränsningarna och bli mer hemmastadd i sin kropp igen.*

Strukturen rymmer två nivåer. Den första nivån reflekterar de begränsningar i tillvaron som sjukdomen medförde och den andra nivån beskriver personernas strävan efter att överskrida begränsningarna i tillvaron och "bli sams" med sin kropp. Upplevelsen av den egna kroppen var en viktig faktor för personernas förmåga att hantera sjukdomen i det dagliga livet. Både männen och kvinnorna upplevde en förändrad självbild, till exempel en känsla av att vara annorlunda i förhållande till andra. Personerna beskrev också hur deras manlighet respektive kvinnlighet påverkades negativt av sjukdomen. Kvinnorna beskrev

känslor av att vara oattraktiva till följd av sjukdomens kroppsliga uttryck, till exempel uppblåsthet eller illaluktande gasavgång. Männen beskrev att de upplevde sig själva som svaga i relation till den traditionella bilden av mannen som stark och osårbar. Skamkänslor och genans över de kroppsliga symtomen bidrog i stor utsträckning till att öka begränsningarna i vardagen både när det gällde socialt liv, arbetsliv och nära relationer. De nära relationerna beskrevs påverkas såväl när det gällde föräldrarskap som relationen till en partner, eller att våga ta steget och gå in i en ny relation. Samtidigt uttrycktes en stark vilja att överskrida begränsningarna för att kunna leva det dagliga livet som andra.

Studie II visade två motsatta positioner som representerade studiedeltagarnas erfarenheter av att vara i patient i mötet med hälso- och sjukvården. Den första positionen; *upplevelser av icke stödjande möten*, bygger på tre teman vilka utgör variationer av erfarenheter präglade av förödmjukelse, osynliggörande och övergivenhet. Personernas egna erfarenheter av att leva med sjukdomen upplevdes inte vara av betydelse för vården. Deltagarna beskrev också känslan av att bli osynliggjord som individ. Dessa erfarenheter beskrevs återverka på personernas självtillit, tilltron till hälso- och sjukvården och förmågan att hantera sjukdomen i vardagen. Känslor av skam uppstod i mötet med hälso- och sjukvårdspersonalen. Den andra och mindre framträdande positionen; *upplevelser av stödjande möten*, kan ses som ett direkt motsatsförhållande till den första positionen. Temat att bli bekräftad som person speglar erfarenheter av möten präglade av ömsesidighet, förståelse och bekräftelse. Personernas levda erfarenheter av sjukdomen respekterades och togs tillvara. Möjligheten för personerna att återskapa upplevelsen av hemmastaddhet i tillvaron föreföll främjas i dessa möten.

Resultatet i *studie III* visade att deltagarna skattade sin övergripande upplevelse av symtomens intensitet signifikant lägre efter patientutbildningen. Statistiskt signifikanta skillnader i självskattningarna kunde också ses när det gällde upplevelser av minskad intensitet av symtomet uppblåsthet, tillfredsställelse med tarmfunktion, samt på sjukdomens inflytande över vardagen. Däremot kunde ingen signifikant skillnad i upplevelsen av smärta påvisas. Personerna i studien förändrade sitt användande av olika copingstrategier. Statistiskt signifikanta skillnader kunde ses i den genomsnittliga användningen av copingstrategierna avståndstagande vilken användes oftare, och flykt –undvikande, vilken användes mer sällan. Strategin självbehärskning användes proportionellt oftare än andra strategier efter patientutbildningen. De personer som uppnått en kliniskt betydelsefull symtomförbättring, hade i större utsträckning förändrat sitt copingmönster än de som inte i lika stor utsträckning uppnått en symtomförbättring efter att ha deltagit i patientutbildningen.

I resultatet av *studie IV* identifierades fyra olika teman: *att lära känna sig själv genom andra; att vara en del av en gemenskap; att förstå sjukdomen som en del av livet som helhet; att tillämpa strategier*. Den patientutbildning som varit i fokus kan ses som ett rum för möjliggörande av lärande, där professionellt stöd och möjligheten att dela erfarenheter tillsammans bidrog till att främja individernas möjligheter att öka sitt välbefinnande och hitta balans i tillvaron. Kombinationen av vetenskaplig och erfarenhetsbaserad kunskap beskrevs av deltagarna som viktig. Tillsammans föreföll detta ha bidragit till en växande beredskap. Denna baserades på en ny förståelse av kroppen som helhet, och på en ökad förmåga att fatta kunskapsgrundade beslut om att tillämpa olika strategier som möjliggjorde ett ökat välbefinnande i vardagen. Emellertid fanns det också personer som inte kunnat känna igen sig i de andra deltagarnas berättelser utan hade upplevt utanförskap. De hade önskat sig möjligheten att få individuellt stöd under patientutbildningen.

SAMMANFATTANDE REFLEKTIONER

Vad som tydligt har framträtt i avhandlingen är att det är upplevelsen av kroppen som främmande och otillförlitlig som utmanar och begränsar personerna i deras dagliga liv, både i relation till sig själva och till andra, samtidigt som det finns en stark vilja hos personerna att överskrida begränsningarna. Ett annat huvudresultat är att patientutbildningen har främjat personernas dagliga liv.

I *studie I* beskrev studiedeltagarna hur de skämdes över sjukdomens kroppsliga uttryck, till exempel uppblåsthet eller illaluktande gasavgång. Kroppsskam, att skämmas över hur man ser ut eller hur kroppen ”uppför” sig, står alltid i relation till andra människor och är ofta kopplat till de värderingar och normer som finns i vår sociokulturella omgivning. Den så kallade civilisationsprocessen av vårt moderna västerländska samhälle påbörjades under 1700-talet och har medfört att våra mest grundläggande kroppsliga funktioner såsom behovet att kissa, bajsas, rapa eller släppa sig, blivit privata och tabubelagda. Hälso- och sjukvården, inklusive vården av personer med IBS, har liksom andra ”aktiviteter” i samhället, med all sannolikhet också präglats av dessa normer och värderingar. Skammen har också en existentiell dimension som innebär att skämmas över sig själv, över vem man är. Den existentiella skammen uppstår i upplevelsen av att vara annorlunda i relation till hur vi skulle vilja vara och hur vi uppfattar att andra uppfattar oss.

Ett möte mellan en patient och en hälso- och sjukvårdspersonal innebär i någon mening alltid ett maktförhållande i obalans. Patienten är den hjälpsökande som förväntas blotta sina tankar och erfarenheter, till en person som ofta är främmande, och i en helt främmande miljö. För en person med IBS handlar det om att berätta om erfarenheter av sjukdomen som är relaterade till tabubelagda och skamfyllda symtom som många av oss lärt oss redan från barnsben att inte tala med andra om. Deltagarna i *studie II* beskrev i huvudsak erfarenheter av möten med hälso- och sjukvården som präglades av upplevelser av förödmjukelse, osynliggörande och övergivenhet, något som har antagits bidra till en nedvärdering av självet, en existentiell skam. Skamkänslor kan sägas vara uttryck för en hotad värdighet. I mötet med patienten är det därför viktigt att hälso- och sjukvårdspersonalen är lyhörd och varsam för att inte ytterligare förstärka känslan av ovärdighet. Att initiera samtal om och bekräfta skammen, kan därför även om avsikten är god, snarast förvärra situationen och öka patientens underläge. Att skapa en ömsesidig relation, där patients erfarenhet står i centrum, blir därför centralt i vårdmötet.

I *studie II* var det tydligt att personerna upplevde en brist på just ömsesidighet. I mötet mellan en patient och en hälso- och sjukvårdspersonal möts också två olika kunskapshorisonter. Vårdspersonalen har sin professionella objektiva kunskapssyn på sjukdomen, medan patienten har sin subjektiva sjukdomserfarenhet. I de möten som beskrevs som ickestödjande, togs personernas erfarenhetsbaserade kunskapshorisont inte till vara. Studiedeltagarna beskrev tvärtom att deras erfarenheter ofta inte alls efterfrågades.

Flera av beskrivningarna i den här avhandlingen visar att de personer som deltog har haft en stark vilja att överskrida de begränsningar i vardagen som sjukdomen medför. Detta kan jämföras med den grundläggande drivkraften till lärande som nämnts tidigare. I mötet med hälso- och sjukvården togs inte personernas egen kraft och vilja att förändra sin livssituation till vara. Istället beskrev personerna att de varken fått utrymme att diskutera sin egen situation, eller tillräckligt med information som de kunde använda för att hitta strategier i vardagen som möjliggjorde ett ökat välbefinnande.

I *studie III* visade personernas självskattningar att de skattade sitt sätt att hantera sjukdomen efter patientutbildningen annorlunda. De fysiska symtomen skattades mindre intensiva, och sjukdomen skattades ha mindre inflytande i vardagen. Ett exempel på en strategi som personernas i studie IV uppgav att de i större utsträckning använde sig av efter patientutbildningen, var självbehärskning. Ökad kunskap om sjukdomen medförde att

personerna kunde anta ett mer avslappnat förhållningssätt till sina symtom. Det som tidigare orsakat oro och rädsla, till exempel svår magsmärt kunde nu mötas med ett större lugn. Ett annat sätt för personerna att ta kontroll kunde vara att använda sig av de andningsövningar de lärt sig under patientutbildningen. Deltagarna beskrev också att de i mindre utsträckning försökte undvika att konfronteras med svårigheter. Deras ökade kunskaper hade gett dem självförtroende att till exempel våga tala med personer i sin omgivning om sjukdomen på ett annat sätt än tidigare.

Patientutbildningen kan vid första anblicken förefalla ganska traditionell i den meningen att den är baserad på föreläsningar som hålls av specialister inom olika områden relaterade till IBS, vilka varvas med gruppdiskussioner och enstaka praktiska övningar. Utbildningen anger således en ambition att utbilda patienten i det som professionen på förhand har ett antagande om att personer med IBS behöver. I resultatet av studie IV framträder dock en bild av patientutbildningen som ett rum för möjliggörande av lärande, som främjade deltagarnas möjligheter att själva uppnå ökat välbefinnande och en känsla av hemmastaddhet både i sin egen kropp och i vardagen. Detta kan beskrivas som ett slags ny ”beredskap”.

Att vara i en grupp med andra i liknande situation innebar inte bara en möjlighet att dela erfarenheter och lära av varandra. Det skapade också en ömsesidighet och en trygghet. Patientutbildningen beskrevs som en miljö där man kunde prata öppet om saker som annars upplevdes som skamfyllda, utan att skämmas eller känna olust. Den hälso- och sjukvårdspersonal som deltog, ansågs underlätta genom sitt avslappnade förhållningssätt till tabubelagda frågor. Patientutbildningen blev ett gemenskapens rum, där personernas erfarenheter av att leva med IBS var den sammanfogande länken. Ålder och kön, till exempel att vara ensam man i en grupp, eller att vara äldre än de övriga deltagarna, upplevdes inte utgöra något hinder för att känna sig som en del av gemenskapen. Däremot fanns det personer som beskrev en känsla av utanförskap därför att de inte kunnat känna igen sig i de andra deltagarnas berättelser. Att till exempel vara den enda i gruppen med förstoppningsbesvär eller täta avföringsträngningar kunde upplevas svårt. Det fanns också personer som beskrev att de upplevde behov av fortsatt stöd från hälso- och sjukvården för att kunna omvandla sin nyförvärvade kunskap till användbara strategier i vardagen.

Både möjligheten att dela erfarenheter med andra i liknande situation, och den kunskap som förmedlades av hälso- och sjukvårdspersonalen, sågs som betydelsefulla komponenter. Ett antagande är att dessa båda kunskapsformer i kombination med den miljö av ömsesidighet och trygghet som patientutbildningen utgjorde, är viktiga förutsättningar för att möjliggöra lärande och främja hälsa hos personer med IBS som ska lära sig att leva med sin sjukdom.

AVHANDLINGENS BETYDELSE

Resultaten pekar på ett antal områden som är väsentliga att lyfta i diskussionen om den framtida vården av personer med IBS, såväl som för framtida forskning:

- Patientperspektivet behöver stärkas. Patientens sjukdomserfarenhet bör vara utgångspunkten i varje möte med hälso- och sjukvården. Vården behöver utvecklas och få ett innehåll som stöttar personer med IBS i deras strävan efter att själva hitta strategier som möjliggör ett ökat välbefinnande i vardagen.
- Den skam som finns förknippad med sjukdomen behöver synliggöras, så att varje möte mellan personer med IBS och deras vårdgivare innebär en strävan efter att bevara patientens värdighet.
- I planeringen av gruppbaseprogram för patientutbildningsprogram för personer med IBS, bör balansen mellan enskilda personers behov å ena sidan och gruppens behov å

andra sidan, beaktas. Ett sätt kan vara att tillämpa en flexibilitet i det vetenskapliga kunskapsinnehållet, och att sätta samman grupper av personer med liknande symtombild. På detta sätt skulle känslan av utanförskap sannolikt kunna minska.

- Olika former av patientutbildning behöver prövas systematiskt, exempelvis enskilda och Internetbaserade alternativ, för att tillgodose behovet av stöd hos fler individer än vad som är möjligt idag. Detta skulle med fördel kunna ske i samverkan med andra aktörer än hälso- och sjukvården, till exempel patientföreningar och studieförbund.
- Föreliggande patientutbildning bör studeras i ett längre tidsperspektiv och i jämförelse med andra modeller.
- Avhandlingen ger begränsad information ur ett genusperspektiv. Detta bör beaktas i framtida forskning.

INTRODUCTION

For the past twenty years, I have been working at Ersta Hospital, mainly in a context directed towards caring for people with gastrointestinal diseases. I have had a number of different professional roles during this time: nurse in an outpatient clinic and in ward settings, consultant nutrition specialist nurse, quality coordinator, and for the past couple of years, head of care development. From these years I carry with me many experiences of encounters with patients, some of which were especially important to my understanding of the great challenge that chronic illness can bring to a person's life. Among these patients were those with irritable bowel syndrome (IBS). IBS is a common chronic functional gastrointestinal disease that does not manifest externally; in fact, people with IBS generally appear to be much healthier than the reality reveals when they speak about their situation.

An extensive body of research has been performed to investigate the cause of IBS and various treatments, but the experience of living with the disease has been paid less attention. In this research project, my main interest has been to learn about illness from the perspective of those who live with the disease. This is grounded in the notion that all human beings have their own unique expertise related to their experience of health, illness, and life. Accordingly, this thesis is about people with IBS and how they experience their everyday life. It is also about the health care system, and how people with IBS experience their many encounters with health care professionals and the support which is offered to overcome the troubles they face during their illness trajectory. The following quotation from a participant in one of the studies serves as an introduction to the everyday life experience of a person with IBS:

One thing is the symptoms themselves then, there has been nausea, there has been diarrhoea, and there has been pain; kind of, not devastating in one day, but more that it devastates you over the course of several days. On a bad day I might wake up around four in the morning with severe nausea, and then I can't go back to sleep. And then there can be diarrhoea up until the afternoon. It's not dangerous, but everything is so... you're just like one huge stomach, that's how it feels.

Then there is the mental bit that I feel, it's a bit like ending up in a wheelchair, or that I can't trust myself. And the part of myself as a friend and partner and parent and colleague and so on, it's turned upside down, my image of myself is also turned upside down, but everyone else looks at me as if, well, I look about the same as before. Sometimes they can see that I feel sick of course, but still, it's those two bits together.

I have a creative job and it's really difficult to be creative in that situation, when I feel sick. But if I succeed with something anyhow, I feel like I've won. But mostly I do long for doing something really simple. And I cheat both at work and with the kids. I try to do, not cheat, but I just try to solve the day simply.

Then of course I have been worried over what could happen. Normally, I'm not particularly afraid of death or so, but when I feel so sick and don't know what it is, then it's tough. And I became very, I became like an old person somehow, I became very sensitive to all change, sleep or, yes, exercise, everything became so particular.

BACKGROUND

LIVING WITH IBS

This thesis looks at IBS from the perspective of the patient. The concept of the patient has been under debate in recent years, because of its historical associations with paternalistic and objectifying health care systems, involving asymmetrical health care relationships between patients and health care professionals. Other terms have been suggested in this discourse, and are used to some extent, for example clients, health care consumers, or customers. In this thesis, the term “patient” is used synonymous to a person with IBS, with own unique experiences of health, illness, and life, who for any reason interacts with the health care system.

When trying to understand as much as possible of a patient’s situation, the biomedical interpretation of the disease is important. However, every human being has their own way of dealing with illness in everyday life. For a chronic disease like IBS, this is a lifelong task. Therefore, the experience of illness constitutes another important perspective in understanding how best to help the patient to achieve wellbeing.

Assuming the patient perspective in the thesis means that there will be an emphasis on literature that takes its departure from people’s experiences of IBS. However, to understand the circumstances under which these experiences are generated, the characteristics of IBS will first be presented.

Characteristics of IBS

A person with IBS is typically troubled by abdominal pain or discomfort and altered bowel movements (diarrhoea, constipation, or a mixture of both). Other common problems are flatulence, bloating, urgency to defecate, a sense of incomplete evacuation of the bowel, early satiety, and sometimes nausea (1).

The worldwide prevalence of IBS among adults is reported to range from 3-25%, depending on methodological matters such as the diversity of definitional criteria, and the sampling and data collection within the studies. It has been suggested that IBS is as common in Asian, African, and South American countries as in the Western world (2-4). In Sweden, the prevalence has been estimated to be 12.5 % (5). People with IBS represent 20-50% of all patients in gastroenterology care, and in primary care they represent 12% of all health care seekers (3, 4).

The peak prevalence of IBS occurs in the third and fourth decades of life (2-4). The disease is up to two or three times more common among women. The reason why women are overrepresented is not fully understood, but in the body of research about gender in relation to IBS it is frequently suggested that the relevant factors include biological differences between men and women, as well as gender and social differences (2-4). The diagnosis is based upon established symptom criteria, of which the most commonly used are the Rome II and Rome III criteria (1, 4, 6). The studies included in this thesis use the Rome II criteria (figure 1).

There is still uncertainty about why some people develop IBS, but according to the literature the disease is best understood as an interaction of psychosocial and biological factors such as genetics, environmental issues in early life, altered motility, visceral sensation, and disturbances of brain-gut interaction, immune-related factors, and post-infectious consequences (4). People living with IBS often experience an impaired

health-related quality of life (4, 7-9). In the absence of a cure, IBS treatments are directed towards alleviating the symptoms and improving the person's ability to manage everyday life with the disease. Treatment is determined by the type and severity of symptoms, and the nature of the associated psychosocial issues. Among the alternatives are bowel medication (laxatives, anti-diarrhoeals, and spasmodics), psychotropic medication (antidepressants and anxiolytics), lifestyle advice, educational interventions, diet and eating habit modifications, and psychological interventions (hypnotherapy, psychotherapy and cognitive behavioural therapy) (4, 10, 11).

<p>At least twelve weeks (not necessarily consecutive) in the preceding twelve months, with abdominal discomfort or pain that has two of three features:</p> <ul style="list-style-type: none"> ▪ Relieved by defecation and/or ▪ Onset associated with a change on frequency of stool; and/or ▪ Onset associated with a change in form (appearance) of stool. <p>Symptoms which support the diagnosis of IBS:</p> <ul style="list-style-type: none"> ▪ Abnormal stool frequency (> 3 bowel movements per day or < 3 bowel movements per week) ▪ Abnormal stool form (lumpy/hard or loose/watery) ▪ Abnormal stool passage (straining, urgency, or feeling of incomplete evacuation) ▪ Passage of mucus ▪ Bloating or feeling of abnormal distension
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Figure 1. The Rome II diagnostic criteria

Experiences of everyday life

When this research project began in 2006, a modest amount of research was available about people's experiences of living with IBS in everyday life. In 1993, Dancey and Backhouse (12) were among the first to present findings from a study that aimed to explore this from the patient perspective. Their study participants, who had responded to a questionnaire which was analyzed partly qualitatively, described IBS as a hidden problem that they did not talk about with others. These persons also described how their bodily troubles restricted their activities and relationships in everyday life, and how they blamed themselves for having caused the disease via their lifestyle and behaviours.

A couple of years later, Meadows et al. (13) explored people's experiences of IBS with a focus on the disease rather than the experience of illness; that is, emphasizing aetiology, onset of symptoms, changes in symptom patterns, and treatments. In 2002, Bertram et al. (14) analyzed a number of focus group discussions, reporting findings similar to those of Dancey and Backhouse (12). The persons participating in these discussions also described how they felt isolated from other people due to the constraints that IBS placed on their everyday lives, and they spoke about their struggle to find a place on an illness/wellness continuum.

In 2006, Fletcher and Schneider (15) presented the first in a series of articles about the experience of living with IBS and inflammatory bowel disease. In this first article, the findings revealed a number of food-related coping strategies used by the participants. Of those, identification of certain trigger foods, choosing healthy food alternatives, and managing stress and food problems related to travel were described to

be the most significant strategies. Finding these strategies was described as a lifelong learning process.

In recent years there has been a gradual development of knowledge and increased presentation of research that explores the patient perspective on living with IBS. Drossman et al. (16) conducted focus group interviews to obtain knowledge about people's experiences of symptoms. Their participants experienced IBS as influencing everyday life, and creating stigma in relation to others. Schneider and Fletcher (17) explored the origin of the negative impact of the disease among women; the participants reported that they often experienced anxiety reactions which triggered a cascade of impact that negatively influenced their wellbeing. The same authors and their colleagues (18) also identified a number of coping strategies used by these women: having a positive attitude, seeking support, controlling the situation and surroundings, ignoring the problem, using relaxation techniques, and becoming knowledgeable about the disease. In three further articles, the same group of researchers continued their exploration by examining food matters related to everyday life with IBS. These articles outlined the participants' changes in dietary patterns before and after the diagnosis (19), and their efforts to manage problems related to food and medication (20, 21). Casiday et al. (22), who studied IBS patients' explanatory models and expectations about the management of IBS, revealed that their study participants perceived identification of symptom triggers to be more important than understanding the origin of IBS.

At the time of the publication of the first article in this thesis, Ronnevig, Vandvik & Bergbom (23) presented a study about people's experiences of living with IBS. Their participants experienced the unpredictability and taboos related to IBS as bringing about constraints and dependency, and considered living with IBS to be a matter of protecting one's dignity to the best of one's capability. To my understanding, this article is the first to provide an existential dimension of what it can be like to live with IBS. Bearing in mind that there might be studies that for some reason were not found, table 1 presents an overview of relevant qualitative studies published in peer reviewed journals.

Experiences of encounters with health care

Encounters between people with IBS and health care professionals might be sporadic or ongoing, and might involve several primary and/or specialist care providers (11, 24). Even though there has been some movement towards a more multidisciplinary approach to care for this group of people, the physician is still most commonly the main caregiver (25). As for many other people with chronic illnesses, the disease and illness management of IBS is mainly conducted by the people with IBS themselves, in the context of their everyday lives. Encounters with health care professionals thus become important opportunities for information exchange, decision making, and moral support.

The experience of illness is always the point of departure for a person with IBS who seek help from the health care system. In supporting the self-management of chronic diseases in everyday life, the literature outlines the importance of acknowledging each person's unique experience of illness (26-28). However, there is substantial research showing that people with various chronic diseases experience difficulties when they take on the role of patients (29-33). Previous research about the patient perspective of health care in relation to IBS has described experiences of insufficient provision of information about the disease and treatment options (12-14, 19, 34), as well as experiences of being met with a lack of understanding, and feelings of not being taken seriously by health care professionals (12-14). Despite being few in

number, these studies provide important insights about the topic, but they also raise further questions. None of the studies had the primary aim of eliciting in-depth understanding specifically about people's experiences of encounters with health care professionals.

Table 1. Chronologic overview of peer reviewed published qualitative studies about IBS

Year	Authors, article	Aim	Study design	Findings
1993	Daneey & Backhouse. (UK). <i>Towards a better understanding of patients with irritable bowel syndrome</i> (12).	Not given explicitly, but from text in the abstract interpreted as being: to learn about the participants' symptoms, medical tests, and feelings about the treatments received, and to discover how IBS affected the lives of the participants.	Qualitative and quantitative data derived from questionnaires answered by 144 individuals from an IBS self-help organization. No information given about the analytical procedure.	Sufferers of IBS have the problem of coping not only with their symptoms, but with the attitudes of others around them. IBS affects work, travel, leisure time, and personal relationships. It disrupts lives. Sufferers may feel guilty, anxious, or depressed due to having a chronic disorder which is seen as having little validity as an illness.
1997	Meadows, Lackner & Belic. (Canada). <i>Irritable bowel syndrome: an exploration of the patient perspective</i> (13).	To detail the journey of IBS sufferers in their attempt to understand and manage their illness, focusing on their perceptions of the origin of illness, their search for treatment, their present management strategies, and their need for information and control.	Face-to-face or telephone interviews were conducted with 14 individuals with IBS recruited from family care practice, along with 12 supportive others identified by these 14 individuals. The study used a grounded theory approach.	The study participants believed that IBS was caused by leading a stress-filled life. They had experienced a lack of knowledge among physicians, making the trajectory of getting the diagnosis a long and hard one, including multiple diagnostic tests, failed treatments, lack of information, and feelings of not being taken seriously.
2001	Bertam et al. (USA). <i>The patient's perspective of irritable bowel syndrome</i> (14).	To understand how IBS affects patients' lives and their interactions with physicians and the health care system.	Focus group interviews were performed with 51 participants in 7 groups, recruited from primary care, newspaper advertisements, and a local IBS support group. The data were analyzed with the help of a "crystallization" technique.	People with IBS view their illness as a chronic condition that is episodic in nature and triggered mainly by stressful events. They feel little control over the initiation, intensity, and duration of their episodes of illness, leading them to a feeling of frustration. They perceive their medical care providers as unsympathetic and of limited help in dealing with their disease. The gap between the patient's and the physician's perceptions of the nature, severity, and consequences of IBS appears to lead to frustration, isolation, and missed opportunities to improve the patient's quality of life.
2003	Kennedy, Robinson & Rogers. (UK). <i>Incorporating patients' views and experiences of life with IBS in the development of an evidence based self-help guidebook</i> (35).	To produce information for the production of a self- help guidebook for people with IBS, through exploring people's knowledge and experience of the disease.	Seventy three participants were recruited, through advertisement in a regional paper, to participate in five different focus groups. Semi-structured interviews were performed and analyzed using the framework technique.	The experience of IBS ranged from occasional discomfort to a major disruption of everyday life. The participants had experience of trying a range of treatments, and had often developed personal coping strategies. However, they still felt insufficiently informed about the origin, nature, and prognosis of the disease.

Year	Authors, article	Aim	Study design	Findings
2006	Fletcher & Schneider (Canada). <i>Is there any food I can eat? Living with inflammatory bowel disease and/or irritable bowel syndrome</i> (15).	To explore the lived experience of women who had been diagnosed with inflammatory bowel disease (IBD) and/or IBS, specifically focusing on the relationship between food and the diseases.	Eight women (five with IBS only, two with IBS and IBD, one with IBD only), recruited from a university, were interviewed once each by three different researchers. The interviews were open-ended. The analytical method is unclear, but appears to be some kind of content analysis.	One of the most significant ways of coping with the illness was centred on food consumption, including identifying trigger foods and making healthy food choices, the impact of stress, and problems associated with food and travel. This trajectory was described as a lifelong learning process.
2007	Bengtsson, Ohlsson & Ulander (Sweden). <i>Women with irritable bowel syndrome and their perception of a good quality of life</i> (36).	To gather information regarding what women with IBS considers a good quality of life (and to create a health care model for these patients).	Thirty four women, identified through a diagnosis register in a hospital, responded by mail to a single written open question about their perceptions of a good quality of life. The data were analyzed inductively with content analysis.	The women's perceptions of a good quality of life were divided into five categories: physical and mental health, social wellbeing, welfare, strength and energy, and self-fulfilment. The authors suggest that according to these findings, a health care model for patients with IBS should include four main areas: treatment of symptoms, confirmation for the patient, confirmation of the diagnosis, and instruction for the patient.
2007	Jamieson et al. (Canada). <i>Seeking control through the determination of diet. A qualitative investigation of women with irritable bowel syndrome and inflammatory bowel disease</i> (19).	To study the lived experience, in relation to diet, of women who diagnosed with IBD and/or IBS. The study specifically explores pre- illness and post-diagnosis dietary patterns of the participants with emphasis on the changes.	Appears to be the same sample, interview occasion, and description of analysis as in the article by Fletcher & Schneider 2006. The interviews are referred to as semi-structured, and the study design is described as being phenomenological.	Three major themes were identified: control, support from family and friends, and adverse behaviours. Diet was the primary behavioural factor manipulated by the participants when attempting to manage their illness. The determination of potential trigger foods/beverages was described as entailing a frustrating process of trial and error, in which only a few of the participants experienced receiving support from health care providers.
2007	Halpert et al. (USA). <i>What patients know about irritable bowel syndrome (IBS) and what they would like to know. National survey on patient educational needs in IBS and development and validation of the patient educational needs questionnaire (PEQ)</i> (34).	To identify ; patients perceptions about IBS; the content areas where patients feel insufficiently informed, and whether there are differences related to items 1 and 2 among clinically significant subgroups	The IBS-Patient Education Questionnaire (PEQ) was developed in two steps, with the first comprising three open-ended focus group interviews including 18 participants, to collect data which would then inform the process of developing the questionnaire. The procedure used to analyze the focus group data is unclear, but appears to be some kind of content analysis.	The focus group interviews revealed that the participants held various misconceptions about the nature and origin of IBS, and that they were mainly interested in learning about foods to avoid causes of IBS, coping strategies, medications, prognosis, and research in the field.

Year	Authors, article	Aim	Study design	Findings
2008	Casiday et al. (UK/Netherlands). <i>Patients' explanatory models for irritable bowel syndrome: symptoms and treatment more important than explaining etiology</i> (22).	To elucidate explanatory models of IBS among patients in primary care, and their expectations of IBS management.	Patients from the UK (n=30) and the Netherlands (n=21) were recruited from primary care. Face to face semi-structured interviews were conducted and analyzed with a modified grounded theory approach.	Despite the dampening effect that the disease was described as having everyday life, the participants made great efforts not to allow the disease to take over their lives. They saw identification of symptom triggers as being more important than understanding the underlying aetiology of IBS. Diagnosis and treatment were described as being confusing and frustrating processes.
2008	Fletcher et al. (Canada). <i>I am doing the best I can! Living with inflammatory bowel disease and/or irritable bowel syndrome (Part II)</i> (18).	To explore the lived experience of women who had been diagnosed with inflammatory bowel disease (IBD) and/or IBS, specifically focusing on the strategies that the women used for coping with these diseases.	See Fletcher & Schneider, 2006.	The participants used a number of strategies to cope with their disease: positive attitude, support, controlling the situation and surroundings, distraction/ignoring the problem, relaxation techniques, and education/knowledge.
2008	Fletcher et al. (Canada) <i>I know this is bad for me but ... A qualitative investigation of women with irritable bowel syndrome and inflammatory bowel disease. Part II</i> (20).	To explore the lived experience of women with inflammatory bowel disease (IBD) and/or IBS, with an emphasis on the dietary patterns of the women before and after the diagnosis. The article specifically examines the adverse behaviours that the women engaged in with respect to the consumption of food, beverages and medications.	See Fletcher & Schneider, 2006.	Three salient themes were identified: engaging in adverse behaviours, the importance of support, and issues with control. Engaging in adverse behaviours was the focus of this article, and included two subthemes: dietary restrictions, and issues with medication. The authors suggest that the data support the claim that the participating women displayed these "inappropriate behaviours" in relation to both food and medication.
2008	Schneider & Fletcher. (Canada). <i>I feel as if my body is keeping me hostage! Exploring the negative impact of irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD) upon university-aged women</i> (17).	To explore the lived experiences of university aged women with IBS and/or IBD, and more specifically to describe the negative impact that these diseases have upon the women's physical and emotional lives.	See Fletcher & Schneider, 2006 for sample and data collection. The design is still a phenomenological one, but the analytical method is here referred to as heuristic inquiry.	A common experience among the participants was that of an anxiety reaction being followed by an attack of illness. This attack was described as triggering a cascade of impact that negatively influenced the women's emotional and physical wellbeing, affecting their overall quality of life.

Year	Authors, article	Aim	Study design	Findings
2009	Schneider, Jamieson & Fletcher. (Canada). <i>One sip won't do any harm: Temptation among women with inflammatory bowel disease/irritable bowel syndrome to engage in negative dietary behaviors, despite the consequences to their health</i> (21).	To explore the dietary lived experience of university-aged women suffering from IBS and/or IBD, in this article specifically addressing the decision-making process.	See Fletcher & Schneider, 2006, for sample and data collection. The design is still a phenomenological one, but the analytical method is here referred to as heuristic inquiry.	The participants occasionally felt compelled to give in to dietary temptations, despite the consequences to their health. The decision-making process involved three personally-controlled parameters: assessing the cost-benefit relationship before engaging in these behaviours; having a physical and/or psychological reliance on medications to treat the resulting symptoms; and controlling the timing and surroundings in which they indulged their negative dietary behaviours.
2009	Lu et al. (Taiwan). <i>IBS: The bodily experiences of Taiwanese women</i> (37).	To explore how Taiwanese women with IBS gain knowledge about the disorder and to study their experiences in using alternative remedies. The study takes a special interest in the cultural bodily perspective.	An ethnographic design was used. Face to face interviews were conducted with 12 women recruited from a specialist care setting. The data were analyzed using a constant comparative method.	The findings demonstrate the impact of a Chinese traditional medicine perspective on symptoms and gender, and how this influenced the women's use of treatments. The participants emphasized that cleanliness, modesty, and reserve were the expected social norms for women, and that problems associated with IBS therefore caused great embarrassment. Alternative therapies were described as being a major part of the participants' management strategies.
2009	Drossman et al. (USA). <i>A focus group assessment of patient perspectives on irritable bowel syndrome and illness severity</i> (16).	To study the patients' perspective of IBS and the factors contributing to its severity	Focus group interviews were performed with 16 patients in 3 groups. Open ended questions were used. The analytical procedure is unclear, but appears to comprise some kind of process of identifying themes.	The participants said that IBS affected their daily function, thoughts, feelings, and behaviours. They described aspects such as uncertainty and unpredictability, with loss of freedom, spontaneity, and social contacts, as well as feelings of fearfulness, shame, and embarrassment. Another predominant theme was the sense of stigma experienced in relation to lack of understanding from family, friends, and physicians.
2009	Ronnevig, Vandvik & Bergbohm. (Norway). <i>Patients' experiences of living with irritable bowel syndrome</i> (23).	To describe people's experiences and the meaning of these, while living with IBS.	A hermeneutic approach was used for the collection and analysis of open ended face to face interviews conducted with 13 participants.	The findings revealed four themes: living with unpredictability (representing the subthemes: not being in control, not being able to trust, and invasion of privacy); preserving dignity (representing the subthemes: living with sacrifice, taking command, and fulfilling obligations); reconciling struggle; and living with co-morbidity.

PATIENT EDUCATION

People with IBS face many challenges in their everyday lives with illness. Many persons perceive their disease-related knowledge to be insufficient (34, 35), and they feel dissatisfied with their inability to influence their own health and life situation (38, 39). One way of enabling people to learn more about their disease and find strategies to manage their illness in everyday life, is through patient education. In the context of chronic illness, various models and approaches to formal patient education are increasingly becoming an integrated part of care.

Patient education is one of the most commonly used general concepts in the literature for describing actions that involve the mediation of knowledge to people about their diseases, and how to manage illness in their everyday lives (26). The goal of patient education depends on the underlying perspective from which the patient is viewed. Decacche and Aujoulat (40), in their presentation of the current state of patient education development in a European perspective conclude that the patient education movement has undergone a shift; from a biomedical model, based on the biological and physiological aspects of health, towards what they claim to be a holistic approach that also involves the social dimension of health. Redman (41) suggests that the ultimate goal of patient education should be to support people's autonomous decision-making.

Kirkevoid (42) emphasizes the transferring of knowledge to patients as a process of enabling learning that is directed towards alleviating the distress and troubles associated with managing the illness in everyday life. This, then, includes information and support to enable the person to reflect on and express thoughts and feelings related to his or her illness and life situation, and to develop the ability to formulate strategies. Hence, Kirkevoid takes a standpoint in which the patient is considered to be a resourceful learner. The concept of enabling within caring has been defined by Swanson (43, 44) as "facilitating the other's passage through life transitions and unfamiliar events". This, like Kirkevoid's theory, implies trusting and supporting the individual to be a resourceful learner with the capacity to grow, heal, and/or practice self-care. Moreover, it involves providing information, explanations, and emotional support in the form of allowing and validating the person's feelings (44). In this explanation, Swanson points out the acknowledgement of the individual.

Stamler (45), in her analysis of the concept of enablement, suggests a holistic framework for patient education that entails the acknowledgement of the patient's means (needs and goals), abilities, and opportunities to learn. When using this framework, she claims, the health care professionals and the facilitators of patient educational interventions share the power of choosing the goal and evaluating the effectiveness of the educational intervention with the patient, in a way that acknowledges the patient's expertise about his or her own illness and life situation.

Related to enablement is the concept of empowerment. One important principle of empowerment is that for a person to become empowered, they need to be actively engaged in the process. That is, power is not given to someone but created within a person (46). Within patient education and health care, the concept of empowerment has been under debate because of its tendency to address outcomes such as self-efficacy, mastery, and control, while coming to terms with disrupted identity and personal change is overlooked. Additionally, several authors have argued that empowerment in clinical practice tends to be an approach that is often claimed in theory, but often misinterpreted or not fulfilled in practice (46-49). Aujoulat et al. (50) describe empowerment as a complex experience of personal change that allows a person to come to terms not only with treatment and self-care, but also with his or her insecurity and threatened identity, and thereby to better self-manage everyday life.

Dahlberg and her colleagues (51, 52) suggest a caring encounter to be an intersubjective and meaningful meeting, in which acknowledgment and growth of the patient is of primary importance. To be able to support the patient, the health care professional has to become familiar with the patient's life situation. A perspective on patient education that takes its starting point in the patient's experience of illness and life situation requires health care professionals to be open and willing to engage in a mutual learning relationship with the patient. Friberg (26) explicated this by conceptualizing the essence of mutual learning encounters between patients and health care professionals as an act of following and letting one-self be followed.

Patient education and IBS

The literature on patient education for people with IBS covers interventions ranging from the provision of booklets (53) and instructions (54), to extensive individual (38, 55) and group-based (56-58) education programs. The findings of these studies reveal improvements among the participating individuals after the interventions, including increased disease-related knowledge (56, 58), health-promoting lifestyle behaviours (nutrition, exercise, stress management) (38, 57), physical symptoms (38, 54, 55, 57), quality of life (55, 56), and psychological distress (55). Group-based educational interventions for people with IBS have been found to be superior to both written information (56) and individual-based alternatives (55). Group-based approaches have the benefit of enabling individuals to share their experiences with others in similar situations. Supportive social relationships are known to significantly promote effective learning for adult learners because of the social and emotional context in which the knowledge acquisition takes place, and personal growth arises from sharing perspectives and testing ideas with others (59).

The research presented above is mainly directed towards biomedical or cognitive matters such as improvement of symptoms, health-promoting behaviours, and enhanced health-related quality of life. These measures all provide valuable outcomes. However, outcomes that are regarded as being successful by the health care professionals might differ from those considered successful by the person who is in the midst of living an everyday life with IBS. Accordingly, these measures provide limited information about the participating individual's experiences of how these interventions have influenced their everyday life as a whole.

THEORETICAL STANDPOINTS

This thesis takes its starting point in a patient perspective where the patient is regarded as a whole person with unique experiences of health, illness, and life (44, 51, 60). The phenomenological ideas of life world and lived body are the basis for understanding the wholeness of a person. Several researchers have emphasized the phenomenological perspective in caring, because it acknowledges the complexities of personhood, health, and illness. According to Dahlberg et al. (52, 61), the life world perspective facilitates a humanizing care practice. Swanson (43, 44), in her theory of caring, defines people as capable, dynamic, growing, self-reflecting, and spiritual beings with a natural desire to be connected with others. Moreover, people are regarded to be unique human beings in the midst of becoming, whose wholeness is made manifest in thoughts, feelings, and behaviors. Swanson stresses that life experiences are influenced by a complex interplay of genetics, spiritual endowment, and a person's capacity to exercise free will. Hence, a person is both shaped by, and shapes, the environment in which they live (44, 62).

Life world and lived body

The concept of life world was originally introduced by the German philosopher and founder of phenomenology, Edmund Husserl, at the beginning of the twentieth century. The life world is the human being's natural taken-for-granted everyday world of common experience. It is the world of everydayness that is made up from personal activities, and communication. It is within the life world that we act, love, feel, think, understand, and relate to others. The life world is the world that is lived bodily, and through which meaning is constituted (60, 63, 64). Merleau-Ponty (65) took his starting point in Husserl's life world, claiming that all levels of existence depart from embodied existence, something he conceptualized as lived body. The notion of lived body offers a holistic view of the body as subjective, as opposed to the common dualistic notion of the body as an object. In caring and related fields within the social sciences, researchers have used the ideas of lived body to interpret and understand the existential meaning of illness. One of the most commonly mentioned of these researchers is Toombs (66-69), who described her own trajectory of living with multiple sclerosis, in which she experienced the body as a broken tool that restrained her access to the world in a profound way. Bullington (70) described people's experiences of chronic pain as a rupture of the natural connection between the body and the world.

The lived body is an inseparable unity of mind, body, and world, which is always oriented towards the world outside itself, in a constant flow. It is the place where the world reveals itself, a consistency of meaning and significance. The body is the medium through which a person intentionally carries out daily tasks and activities, and through which a person comes to know the body not through abstracting it but through living it. In other words, we do not *have* our bodies; we *are* our bodies. A person's embodied presence in the world is the necessity of all knowledge and experience (65, 70).

The harmony of a situation is based on the correspondence between the embodied subject and the meaning of the situation. This harmony is laid down in meaning structures, which are stable patterns of experience that tell a person how to respond to various situations and how to understand his or her everyday life world. These structures free the person's attention from having to form the fundamentals of experience over and over again. Meaning structures constitute bodily, psychological, and social ways of being oriented towards the world. They allow a person to experience the world as comprehensible and manageable, and they present the world as familiar and known. Throughout life all human beings are continually confronted with situations that challenge their laid-down meaning structures, creating the need to modify their bodily, psychological, and social ways of being in the world (65, 71).

Learning; a process of being in the world

Another important standpoint, especially in relation to the final two studies within this thesis, is to regard each patient as a resourceful and capable learning person. Jarvis (72) has proposed a learning perspective that takes its point of departure firstly from the life world of the individual and secondly from the recognition that a person is always part of a socio-cultural surrounding, constantly in interaction with other people. According to Jarvis, our sense of self stems in part from the reflection of how we perceive that others perceive us through our actions in the external world, and we may actually learn to esteem ourselves because of what we do or because of the way in which we are received by others. Jarvis considers a sense of self-esteem to be a major factor of our personhood that can be understood as something acquired as a result of our learning experiences

(72). He explains that learning is the driving force of human change, through which the human essence emerges and is nurtured. It is the process of being in the world. Hence, learning is not just what is learned but what the learner is becoming as a result of doing, thinking, and feeling. At the heart of this process, therefore, is the learner as a whole person (59, 72). Linked to this, Knowles (73) in his andragogy of adult learning, pointed out that for any situation in which the experiences of adult persons in educational interventions are ignored or devalued, this may be perceived by those adults as a rejection of themselves as persons.

Jarvis defines human learning as “the combination of processes whereby the whole person – body (genetic, physical and biological) and mind (knowledge, skills, attitudes, values, emotions, beliefs and senses): experiences a social situation, the perceived content of which is then transformed cognitively, emotively or practically (or through any combination) and integrated into the person’s individual biography resulting in a changed or more experienced person” (72, p.13).

The significance of experience and disjuncture

Learning always begins with the transformation of experience. Our action is always in the world, and our experiences always involve engagement with the world; these experiences then become the data on which our own thinking is based. It is what we do with our experience that is the basis of our understanding about learning (59, 72).

Our experiences occur at the intersection of the inner self and the outer world. Learning always occurs when the two are in some tension or disharmony, a state that may be described as disjuncture. Jarvis states that disjuncture is the gap between the individual’s biography and perception on the one hand, and his or her construction of the experience of the external world on the other (72). The desire to overcome this disjuncture and to return to a state of harmony can be regarded as a fundamental motivation force in learning. Through a variety of ways, we give meaning to our sensations, and our disjuncture is resolved. An answer to a more or less implicit question may be given by another person, acquired incidentally in the course of everyday living or through self-directed learning, and so on. Once we have acquired a new answer, we have to practice it in order to commit it to memory. Since we do this in our social world, we will receive feedback which confirms that we have achieved an acceptable resolution; if this does not occur, we have to start the process again. As we become more familiar with our socially acceptable resolution and memorize it, we are in a position to take our world for granted again (72).

A phenomenological perspective on health and illness

Learning to adapt to chronic illness means learning to inhabit a new world. A person’s transformation of his or her ways of seeing, moving, and even feeling and thinking, are all a part of managing challenging situations. From the phenomenological perspective of the body as lived, illness can be interpreted as a disruption of a person’s life-world, replacing the taken-for-granted mood of the lived body with increased awareness of, and unfamiliarity with, the broken body (66, 67). In this thesis, Svenaeus (63, 74, 75) phenomenological ideas of health and illness have provided an alternative way of understanding the lived experience of illness among people with IBS. Svenaeus built further on the work of Heidegger, Gadamer, and Merleau-Ponty in developing this theory. He explicates how being ill is essentially characterized as a state of unhomelikeness, in which we are alienated from the way we feel at home in our bodies.

Health, as opposed to illness, is a non-apparent attunement. It is a rhythmic, balancing mood that supports our individual understanding of the world as homelike and taken-for-granted. The balance of health refers to the natural way human beings find their place in the world of intersubjective meaning; a way of being in the world. However, the familiarity of our life world is always in some way pervaded by homelessness. This homelessness is a basic and necessary condition of human existence, related to our finitude and dependence on others and otherness. We are in a world that we cannot entirely control. Health is thus to be understood as a state we are in when everything is flowing smoothly, naturally, and imperceptibly. It is a balanced rhythm of life, a healthy mood of attunement. As such, it can be described as a being-at-home that keeps the not-being-at-home in the world from becoming apparent. It is a feeling of homelikeness. When we are ill, the meaning patterns of our being in the world are fractured, and our lives get out of tune. Our basic feeling of homelessness is stressed by illness, and thus brought to attention; our being at home becomes unhomelike. The mood of illness manifests itself in prominent ways that colour our whole existence and understanding. This is not an immediate experience, but a gradual transformation of the healthy homelike attunement into an unhomelike mood of illness (63, 74, 75).

The concept of unhomelikeness has previously been used in studies of chronic illness to attain a deeper understanding, for example about the experience of chronic exhaustion disorder (76). In addition, Zingmark (77) and Rasmussen et al. (78, 79) used related concepts referring to the existential way of being in the world of illness.

THESIS RATIONALE

A review of the literature reveals a limited number of studies about the patient perspective of IBS, outlining experiences of etiology, onset of symptoms, changes in symptom patterns, treatments, and efforts to cope with the disease in everyday life. Hence, there is a need for complementary studies that take their starting point in a caring perspective that acknowledges the experience of life world and of the body as subjective and lived. There is also a need for improved knowledge about the meaning of being a patient with IBS in encounters with health care professionals, and a deeper understanding of how people experience the support which is offered by the health care system.

People with IBS represent a large group of health care seekers that often feel insufficiently informed and find it hard to manage their illness in everyday life. Educational interventions have previously focused on evaluating biomedical and cognitive outcomes. There is a need to study, from the perspective of the patients themselves, new educational models that can serve as alternative or complementary care models that facilitate learning, and that have the potential to support people in finding their individual ways of achieving wellbeing in their everyday lives with IBS.

AIM

The overall aim of this thesis was to obtain enhanced knowledge and a deeper understanding of the lived experience of irritable bowel syndrome in relation to everyday life and health care encounters, and to study the influence of a group-based patient education program on people's everyday life with illness.

Specific study aims:

- I. To describe the phenomenon of living with irritable bowel syndrome from a life-world perspective.
- II. To deepen the understanding of what it is like for a person with irritable bowel syndrome to be in the patient position in encounters with health care.
- III. To evaluate the influence of a group-based patient education program about irritable bowel syndrome, on people's ability to manage their illness in everyday life.
- IV. To explore people's experiences of participating in a multidisciplinary group-based patient education program for people with irritable bowel syndrome, and study the influence of this program on the participants' everyday lives.

METHODS

The design of this thesis was based on the overall aim of obtaining enhanced knowledge and a deeper understanding of the lived experience of IBS in relation to everyday life and health care encounters, and to learn more about the influence of a group-based patient education program on people's everyday lives with illness. The thesis consists of two parts. The first two studies (I and II) are directed towards the lived experience of IBS in relation to everyday life and health care encounters, while the second two (III and IV) focus on the patient education program.

The main interest during this work was to learn from the patient. Considering this along with the above mentioned theoretical standpoint, of each individual being a unique and experienced person, a qualitative approach was used for most of the research, with study III being the one exception. Study I used a descriptive phenomenological method and studies II and IV were guided by the interpretive description approach. In study III, quantitatively-treated self-assessment questionnaires were used. An overview of the research design of all studies in the thesis is provided in table 2.

Table 2. Overview of research design of studies I-IV within the thesis.

Study	Design	Sample	Data	Method
I	Qualitative descriptive	9 participants (7 women/2 men)	Individual interviews	Phenomenological method
II	Qualitative interpretive-descriptive	9 participants (7 women/2men)	Individual interviews	Interpretive description
III	Quantitative evaluative	51 participants (45 women/6 men)	Self assessment questionnaires	Statistical methods
IV	Qualitative interpretive-descriptive	31 participants (27 women/4 men)	Focus group interviews	Interpretive description

SETTING AND STUDY PARTICIPANTS

Studies I and II

In studies I and II, nine participants (seven women and two men, from a total of eleven invited) were consecutively and purposefully recruited from a gastroenterology outpatient clinic in a Swedish hospital, in 2006. The participants were all on a waiting list for the group-based IBS patient education program being the focus of studies III and IV. The participants were included via a telephone call made by an independent research nurse. Those who were interested in participating were sent written information about the study and a form to give written consent. At the time of inclusion, each person was informed orally about the right to withdraw from the study at any time without having to present a reason. This was also included in the written information. Once they had returned the consent, an appointment for the first interview was scheduled via a telephone call made by the researcher (CH).

Inclusion criteria

For the purpose of gaining rich and concrete descriptions, we sought individuals with a long illness trajectory (IBS diagnosis >3 years prior) who were willing to share their stories. Study I aimed to capture one active part of life in relation to work, studies and family life, and therefore participants aged between 25 and 55 years of age were invited. For the purposes of study II, the participants were also expected to have had multiple experiences of encountering a variety of different health care providers for IBS problems.

The participating individuals

All participants spoke and understood Swedish with no interpretive assistance. They were aged 28-48. Their health care consumption had varied over the years, but they all had a long history of seeking help for IBS-related problems. All participants used medical treatments and, to various degrees, special diets. Seven had previous or current experience from psychological or psychiatric treatment. All nine had academic degrees and worked or studied full-time or part-time, with the sole exception of one woman who was on long-term sick-leave. Six of the nine participants were married or in a relationship. Four of them were parents.

Studies III and IV

In studies III and IV, all 87 individuals (73 women, 14 men) on the waiting list for the above mentioned group-based IBS patient education program were sent a letter of invitation to participate in 2007-2008. The letter included information about studies III and IV, a form to sign a written consent, and a pre-paid return envelope. In the study information, the right to withdraw from the study at any time without having to present a reason was pointed out.

Inclusion criteria

The inclusion criteria for the studies were prolonged IBS problems (>3 years) and diagnosis according to the Rome II criteria (1, 4, 6). The exclusion criterion was ongoing psychological or psychiatric treatment. According to the previously-mentioned

clinical routines, the participants were also evaluated by a gastroenterologist at the clinic.

The participating individuals

Of the 56 persons who initially agreed to participate in both studies, five were excluded after completing the initial self-assessment questionnaires for study III, because they never attended the education program. Three of these five did not participate due to work-related or study-related time constraints, and the remaining two for unrevealed personal reasons. Hence, a total of 51 people (6 men, 45 women) aged 22-71 years (mean age 41 ± 14) participated in Study III. The majority of these (35 of 51) were married or cohabitating.

In study IV, the participants consisted of 31 individuals (27 women, 4 men), aged between 22 and 70 years. Among those who dropped out, four clearly stated that they had changed their minds about participating in the focus group interviews, while the others mostly cited time or illness constraints. An overview of the inclusion and dropout rates of studies III and IV is provided in figure 2.

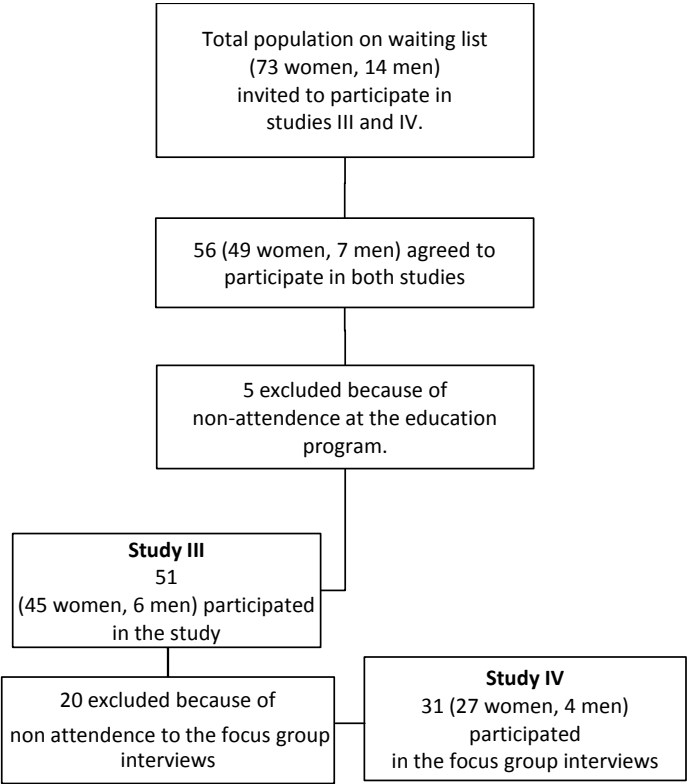


Figure 2. Inclusion chart, studies III and IV

QUALITATIVE METHODOLOGY

The descriptive phenomenological method

In study I, it was the phenomenon of living with IBS from a life world perspective that was sought, and therefore the descriptive phenomenological method as described by Giorgi (80-82) was used. The method was developed for researching psychological phenomena but has been used frequently in caring science research. This method strives to describe and highlight the structure of a certain phenomenon by capturing as closely as possible the way in which the phenomenon is experienced within the particular context in which it takes place (81). The method follows what Giorgi calls a modified Husserlian approach (82). Husserl aimed to establish phenomenology as a rigorous science directed towards the study of how human meaning is constituted. He claimed that knowledge could only be achieved within the act of consciousness, and hence wanted to clarify how an object presented itself to consciousness. Accordingly, phenomenology can be described as the study of structures of phenomena as they appear to consciousness. A phenomenon, then, is anything that can present itself to consciousness (81, 82).

In the descriptive phenomenological method, the researcher obtains concrete descriptions of experiences from those who have lived through situations in which the phenomenon of interest took place. What is sought is a description that is as faithful as possible to the actual lived experience. Next, the structures of these concrete experiences are sought. This is done through systematic determination of the higher-level (abstracted) invariant meanings belonging to the structure (82). The analytical procedure is described in detail in relation to the data analysis of study I.

When taking a phenomenological attitude in research, in order to study the way in which consciousness intends or constitutes its object, it is important that the researcher endeavours to put aside his or her pre-understanding and prior experience of the phenomenon being studied, by assuming the so called phenomenological reduction. The scientific phenomenological reduction entails the suspension of all interest in the existence of the real world and the objective qualities of things, in order to concentrate on an area that is non-thematic and impossible to see as long as the objective perspective is dominant. The scientific phenomenological reduction differs from the transcendental reduction in the sense that it does not retreat to the highest perspective of consciousness, one is closer to the level of lived reality (82).

The systematic analysis of descriptions involves the act of free imaginative variation, which means that the data are imagined to be different from what they are in order to find out higher-level categories that retain the same caring meaning but are not embedded within the same conditional particulars. Unlike philosophy, this procedure is not pushed to a universal level, but to a level of generality that is appropriate for revealing the caring characteristics of the phenomenon being studied (82).

Interpretive description

Studies II and IV aimed at gaining a developed understanding about people's experiences of clinically-situated IBS health care, and so interpretive description was used. Interpretive description is an inductive approach to qualitative research that has been developed by Thorne et al. (83-85) over the past two decades. The basis of interpretive description is smaller-scale qualitative inquiries about clinical phenomena of interest to the health care disciplines. As such, it recognizes that reality is complex,

contextual, constructed, and subjective, and thus can only be studied holistically. The approach is inspired by established methods within the social science tradition, particularly phenomenology, grounded theory, and ethnography.

The idea of interpretive description is to take inspiration and extract elements and systematic ideas from these methods, and let the nature of the data guide the choice of a suitable analytical approach, rather than being constrained by one specific method. Within the interpretive description approach, previous empirical and theoretical knowledge is regarded as a fore-structure to a new inquiry (85); this differs from the above-described phenomenological method, where pre-understanding must be put in brackets. During the analyzing and interpretation of data in interpretive description, the researcher is challenged to look beyond the self-evident within a clinical issue, by documenting patterns and themes and by reconfiguring what is found into a form that has the potential to shift the angle of vision at which the phenomenon is generally considered. When articulated in a manner that is authentic and credible to the reader, findings drawn from interpretive description should represent valid descriptions of sufficient richness and depth, in a specific field of contextual understanding, that will inform clinical care practice (85, 86).

QUANTITATIVE METHODOLOGY

Because the purpose of study III was to study the influence of a clinically-established education program, an evaluative before-and-after research design as described by Brink and Wood (87) was used. This design has previously been used to evaluate educational programs in other disease contexts, e.g. Parkinson's disease (88). Evaluative designs are intended to measure the effects of clinical intervention programs. One important feature of the evaluative research design is to provide adequate control participants so that a model for statistical testing can be used to establish the effects of the program. In the before-and-after design, each study participant acts as his or her own control (87).

In using the evaluative research design, it is assumed that there are measurable objects for the program that can be used as a basis for evaluation, and that there are methods or tools available for measurements that match the purpose of the intervention (87). In study III, the focus was on whether the participants changed their use of different coping strategies in everyday life with illness, after the education program. Because IBS-related symptoms are known to be troublesome and bring about various concerns, fears, and limitations in people's everyday lives, potential differences between the participants' self-assessments of symptom severity before and after the education program were also evaluated. Two self-assessment questionnaires were used: the Ways of Coping Questionnaire (89) and the IBS Severity Scoring System (90).

The Ways of Coping Questionnaire

The Ways of Coping Questionnaire (WCQ) was developed more than twenty years ago by Lazarus et al. (89, 91). The questionnaire was chosen for this study because of its roots in the holistic model of stress and coping. It assesses emotions, thoughts, and actions that individuals employ to cope with stressful encounters of everyday living. It is contextual and process-oriented, meaning that it focuses on what a person actually thinks, feels, and does in a specific situation (89). The Swedish version consists of 45 items representing 8 different coping strategies (figure 3) (92). Each item is responded to on a scale of 0-3, with a higher score indicating that the respondent agrees more strongly with the statement. The scores for all items in each coping strategy are added to

calculate the sum of average responses. This is presented as raw scores or the mean frequency of efforts used on a specific strategy. The raw score for all eight scales, divided by the sum of average responses, is presented as a relative score, which can be described as the proportion of total coping efforts used on a specific coping strategy (89). The WCQ has been used previously for the assessment of coping strategies on people with IBS in the United States (93), but the Swedish version has not been used in the IBS-context.

- *Confrontational coping*: efforts to alter the situation as well as hostility and risk-taking.
- *Distancing*: efforts to detach one self and create a positive outlook.
- *Self-controlling*: efforts to regulate one's feelings.
- *Seeking social support*: efforts to seek informational, tangible, and emotional support.
- *Accepting responsibility*: acknowledging one's own role in the problem and attempting to put things right.
- *Escape-avoidance*: wishful thinking and efforts to avoid the problem.
- *Planful problem solving*: deliberate problem-focused efforts to alter the situation.
- *Positive reappraisal*: efforts to create positive meaning by focusing on personal growth.

Figure 3. Coping strategies included in the Ways of Coping Questionnaire

The IBS Severity Scoring System

The IBS Severity Scoring System (IBS-SSS) is an established and frequently used questionnaire which was developed by Francis et al. (90) to rate the experienced severity of IBS symptoms on a visual analogue scale (0-100 mm). The idea of the scale is that the higher a person scores, the more severe they experience their symptoms to be. The overall score is calculated from five items: pain severity, pain frequency, abdominal bloating, dissatisfaction with bowel habits, and overall influence on everyday life. Total scores range from 0-500, and a decrease of ≥ 50 on the total score is regarded to be a clinically noteworthy improvement. The questionnaire also contains nine questions about extra-colonic symptoms related to IBS. These questions provide additional information but are not used for scoring purposes (90).

The Ways of Coping Questionnaire and the IBS Severity Scoring System are both attached in the appendix.

DATA COLLECTION

Studies I and II

The first two studies (I, II) were aimed at developing new knowledge based on a deeper understanding of the meaning of lived experience of IBS in relation to everyday life and health care encounters. Accordingly, qualitative interviews were chosen, and conducted in 2006. Each participant was interviewed twice, to capture the two different areas of interest for both studies. The study participants were informed orally and in writing about the purpose of the interviews, both at the time of the study invitation and at the time of the interviews. All interviews were carried out by the same researcher (CH), in a quiet environment away from the hospital area, to ensure comfort and privacy.

In study I, the purpose was to gain concrete and rich descriptions capturing the phenomenon of living with IBS. During these interviews, the participants were encouraged to describe their experiences of everyday life with IBS as concretely as possible. The opening question was “Can you describe your experience of living with IBS in everyday life?” To promote concreteness and richness, the participants were asked follow-up questions such as “What did you think or do then?”, and “Can you tell me more about it?”

The second set of interviews, representing the data collection for study II, was conducted 1 to 4 weeks after the first interviews. The opening question for these interviews was, “Can you tell me about your experiences of encounters with health care in relation to your IBS problems?” To promote rich descriptions, participants were asked follow-up questions such as “What did you think or do then?” and “Can you tell me more about it?” Follow-up questions were also used to cover the areas of interest for the study: experiences of attitudes and knowledge among health care professionals, experiences of participation in one’s own health care, experiences of information and support, and experiences of being diagnosed with IBS.

All interviews on both occasions ended with a short summary of the main content of the interview. The summary was made by the researcher (CH) with the purpose of giving the participants the opportunity to add further information about issues that were brought up during the interviews, if they felt something had been missed or not fully clarified. The interviews in study I lasted between 55 and 120 minutes, and those in study II between 45 and 75 minutes. The interviews were recorded on an mp3 player. Two of the interviews in study I were transcribed verbatim by the researcher, and all others in both studies by professional transcribers.

Studies III and IV

The patient education program

The group-based multidisciplinary patient education program in studies III and IV was developed a decade ago in a Swedish hospital, and has since then been an established part of clinical care at this hospital. It is based on the idea that a combination of scientific knowledge provided by health care professionals and illness experiences shared by the participants can facilitate new knowledge that can be transformed into useful strategies to manage everyday life with illness. The content and design of the program (table 3) is based on many years of experience of working with people with IBS, among the members of the hospital’s multidisciplinary IBS team. One feature that is considered key to the learning process is the facilitation of opportunities to share experiences with others in similar situations.

Participants are referred to the education program by gastroenterologists in or outside the clinic. Mainly for organizational reasons, only about 6% (n=120) of the total IBS population at the hospital had the opportunity to participate in the education program at the time of the studies (2007-2008).

The education program is preceded by a one-hour scheduled encounter with a registered nurse from the IBS team, a couple of weeks before the program starts. During this encounter, the nurse provides information about the features and content of the education program, and the persons are invited to share their experiences of illness and to express presumptions and expectations about the program. Feelings about being in a group with other people are also discussed. All participants receive an IBS guidebook that is handed out prior to, or at the time of the introductory encounter. The guidebook, which was written by Simrén (94), consists of two parts that together provide an

introduction to the biomedical IBS-related topics that are later brought up in the education program.

The program is held in groups of 12-15 adult participants of mixed sexes and ages, on five consecutive weekdays (Monday–Friday, one week) for five hours each day. During all five days, lectures are combined with group discussions. Efforts are made to create an atmosphere of openness and ease, and group interaction is continuously encouraged. The nurse who initially encountered each person is present during all sessions, and has the role of supporting group discussions and coordinating the program. During the study period, there were no changes of the schedule or facilitators within the patient education program.

The waiting list for the patient education program

At the time of studies I and II, patients could be referred to the patient education program either from primary care physicians or gastroenterologists outside the hospital, or from the gastroenterologists at the clinic. The eligibility criteria for joining the waiting list at this time were prolonged IBS problems (>3 years) and diagnosis according to the Rome II criteria (8). The exclusion criterion was ongoing psychological treatment. Patients that for some reason were not likely to benefit from the education program were not placed on the waiting list. This could for example be those with gastrointestinal co-morbidities, or those who expressed concerns about being in a group with others. This evaluation was generally made by the nurse within the IBS team, in cooperation with the responsible gastroenterologist. When participants were recruited to studies III and IV, the routines had been changed at the clinic; with all patients having to be evaluated by a gastroenterologist at the clinic before being placed on the waiting list.

Table 3. Schedule for the group-based patient education program

	Daily sessions	Facilitators
A couple of weeks before the program starts	A scheduled encounter with a registered nurse from the IBS team. The nurse provides information about the features and content of the education program, and the participants are invited to share their experiences of illness, and to express presumptions and expectations about the program. Feelings about being in a group with other people are also discussed.	Nurse from the IBS team
Day 1	Practical issues, schedule for the week. Efforts are made to create a comfortable atmosphere, by inviting all participants to introduce themselves and their illness.	Nurse from the IBS team
	Overview of the healthy anatomy and physiology of the gastrointestinal tract, IBS pathophysiology and treatment alternatives.	Gastroenterologist
	Emotional and cognitive aspects of managing illness in everyday life.	Psychologist
Day 2	Bowel evacuation problems, constipation, and faecal incontinence.	Biofeedback nurse
	Physiology of pain in general and pain in relation to IBS in particular. Information about possible pain-relieving treatment alternatives.	Anaesthesiologist
Day 3	Food-related problems and eating habits in relation to IBS. General advice.	Dietician
	Introduction to hypnosis treatment and what is known about the benefit of hypnosis in relation to IBS. Invitation to try hypnosis in the group setting.	Psychologist
Day 4	Breathing patterns, body awareness, stress, anxiety, and pain. Relaxation exercises.	Physiotherapist
	Existential issues. Invitation to share thoughts and feelings about one's illness and life situation.	Hospital deacon
Day 5	Summary of the week. Invitation to reflect on and share thoughts and feelings about everyday life with illness.	Nurse from the IBS team
	Follow-up questions. Evaluation of the week.	Gastroenterologist and nurse from the IBS team

Study III was aimed at studying the influence of the patient education program on the participants' ability to manage their illness in everyday life. The self-assessment questionnaires IBS-SSS (89) and WCQ (90, 92) were mailed to the study participants, together with a return envelope, after their agreement to participate in the study, and 2-3 months after their participation in the education program. Reminders with new questionnaires and return envelopes were mailed on up to three occasions (three, six, and nine weeks later), to those who did not return their questionnaires, both at the initial and the follow-up measure. Those who also participated in the focus group interviews in study IV were invited to choose whether to return their questionnaires by mail, or bring them to the interview occasion.

The WCQ is contextual and directed towards the way a person thinks, acts, and feels in a certain situation. In the introductory part of the questionnaire, before answering the questions, the participants were instructed to think about and describe in writing any everyday life situations that they experienced as particularly difficult in relation to their illness. The questions were then to be scored bearing this contextual situation in mind. The situations these study participants most commonly described to be troublesome were those involving close relationships, work, or social activities.

The aim of *study IV* was to attain a deeper understanding about the influence of the education program on the participants' everyday lives as a whole. Seven focus group interviews were held with 2-6 participants, all of whom had also participated in study III. Of the 31 persons, 4 were men, participating in 4 different groups.

The choice of using focus groups was based on the underlying assumption that we as human beings are products of our environment and are influenced by people around us, and thus our attitudes and perceptions are developed in part by interaction with other people (95). Focus group interviews enable people to explore and expand their experiences and views about a certain topic, revealing rich experiential data that would be less easily accessible in one-to-one interviews (96, 97). Consequently, the key feature of focus groups is the active encouragement of interaction among participants. The researcher can achieve this by encouraging participants to talk to one another; asking questions, exchanging anecdotes, and commenting on each others' experiences and points of view (98). Another reason for choosing focus groups was that they are considered to be appropriate for evaluative research of programs such as the patient education being studied, and especially for eliciting in-depth understanding about a topic that has previously been studied quantitatively (98).

The focus group interviews, which lasted approximately 120 minutes, including introduction and presentation of moderators and participants, took place in a quiet area in the hospital. The room had a round table, enabling all focus group participants to see each other clearly. Efforts were made to create a relaxing atmosphere, by removing potentially-distracting technical or administrative equipment and unnecessary furniture. Hot and cold beverages, fruit, and biscuits were offered when the participants arrived. The interviews were conducted by a moderator (CH) and an assistant moderator (E SB), who sat opposite to each other in order to facilitate eye contact. The role of the moderator was to pose questions, expand topics, and monitor and encourage the group interaction. The assistant moderator's primary task was to take notes about the placing of, and interaction between, the focus group members, and about the topics that were brought up during the interviews.

The interviews were recorded on an mp3 player. To facilitate recognition of the different participants' voices and names during the transcription process, and to make

the participants feel comfortable with the situation, all persons present, including the moderators, were asked to introduce themselves before the interview started.

During the focus group interviews, the moderator used a thematic interview guide based on the aim and features of the education program. The introductory question was “Can you please tell me about your experiences of the patient education program?” Depending on the spontaneity of the interaction and introduction of topics, follow-up questions were asked to stimulate the interaction and capture the variations of experiences among the focus group participants. These questions included “Can you tell me more about this?”, “Do any of you have different experiences or opinions?”, and “How do you feel about this?” At the end of the interviews, the focus group participants were encouraged to discuss their experiences of what the education program had meant to their everyday lives as a whole.

Before closing each interview, the assistant moderator made a short summary of the topics that had been brought up, and the focus group participants were invited to make comments. If they felt something had been missed out, they were invited to add to the summary, or clarify. After the interview, the moderators held a debriefing about the discussion and interaction.

ANALYSIS OF DATA

Study I

The interviews in study I were analyzed according to the phenomenological method of Giorgi (80-82), which has four characteristic steps. First the entire description was read to get a sense of the whole. Next, meaning units were extracted. This step was important as it allowed handling of the large amount of raw data and because it helped clarify implicit matters that would otherwise have been hard to identify.

In the third step, the meaning units were transformed into key constituents. This transformation process had several purposes. The first was to transform the implicit to the explicit; this was done from the perspective of caring. This aspect allowed the analysis to uncover meanings that were lived by the participants, but not articulated or brought fully into awareness. The second purpose was to make the analyses less situation-specific. Seeking the caring meaning of a situation partly meant moving away from the concrete lived situation as an example, and instead clarifying what it was an example of. The third purpose was to go over the previous transformations in order to identify the key constituents that were essential to accounting for the concrete experiences of living with IBS.

In the final step of the analysis, the key constituents were synthesized into a consistent overall structure. The structure refers both to the key constituents and to the relationship among them. In order to fully understand this relationship, a holistic view needed to be taken. The transformations articulated in the study were verified by one of the co-authors. Examples of transformations into key constituents are presented in table 4.

Original text	Transformation 1	Transformation 2	Key constituents	Structure
Your whole role as a friend and husband, colleague and all that, it's turned upside down, your self-image is also turned upside down, and everyone else sees you as if you were the same as before, and still you're not. Those two pieces together.	S is describing how his role as a friend, husband and colleague has been turned upside down. S says that his self-image is also turned upside down. S is describing how other people retain their image of him as healthy. S is describing how he compares himself to how he was before he fell ill. S is describing how he is affected by the differences in how others perceive him in relationship to how he sees himself.	S's self-image is challenged in relation to how others perceive him.	Having an altered self-image.	Living with IBS means struggling with an unfamiliar and unreliable body. Tiredness, distrust, and shameful feelings towards the body bring about limitations in everyday life. At the same time, living with IBS means having a strong will to exceed the limitations and become familiar with one-self
And when I told him about it [telling a partner about the disease], that was a bit embarrassing maybe. I think it is. I don't know if it's connected to my femininity, but I have been a bit ashamed over this, it's a little embarrassing.	S says that it was a bit embarrassing to tell her partner about the disease. S says that she does not know whether her femininity is connected with the reason she thinks it is embarrassing to talk about her troubles with the disease.	S has been embarrassed by the troubles the disease has caused her.	Feeling ashamed.	
Yes, but now, when I was supposed to go out and work and that, then I felt that I couldn't trust my stomach, that was actually damned annoying.	S says that when he was supposed to go out and carry out a job he felt that he could not trust his stomach. S felt that it was very difficult.	As a consequence of the disease S does not dare to trust his own body.	Distrusting the body.	
I can feel like that, just because I work with children too, that I get more easily irritated at them and so on. So it can be hard in that way, because sometimes it feels like they get to take the blame that I don't have the same patience.	S is describing that she is more irritable at work because of her disease. S thinks it is particularly hard since she works in child care, where great demands are made upon her patience. S feels that she does not have the same patience as before. S says that this has negative consequences for the children.	Reduced patience is a consequence of the disease and S feels that the children are affected by that.	Blaming one-self.	
I used to go horse riding a lot, but in the end I just felt - I can't do it. I just don't seem to have the energy to move.	S says that she has lost her energy to do the activities in her spare time that she used to do a lot. S says that she does not have the energy to move.	Tiredness is a consequence of the disease and S feels that it limits her possibilities of being active.	Feeling tired.	
Then I know, then I pack my pills or whatever medication I have, I have sort of learned that, I just have to pack them up. And then it works almost better than at home [about travelling].	S is describing that she has found solutions to problems when dealing with the disease in connection to traveling. S says that when she does that her stomach works better than at home.	S has found solutions to problems when dealing with daily activities.	Finding solutions.	

Table 4. Examples of transformations of meaning units into key constituents in study I

Studies II and IV

The data analysis in studies II and IV was guided by the interpretive description approach. Although the analytical principles were the same in both studies, there were some differences in the analytical processes, mainly related to the nature of the data. Therefore they will be described separately. The main principles of the data analysis in both studies are illustrated in figure 4.

The analysis in *study II* proceeded according to the following steps: First, the interviews were listened to and the transcriptions were read several times to get a sense of the whole. Each text was organized and coded broadly (e.g. descriptions that involved feelings of being ignored), guided by analytic questions, thoughts, and possible premature interpretations. The NVivo 8 computer software package (99) was used to assist with this early stage of data organization.

According to Thorne (85), trying to apprehend the overall picture will stimulate more coherent analytic frameworks for interpretive description than will sorting, filing, and combining vast quantities of small data units. During the process of organizing and coding the data, analytic notes were written as comments or questions. The process of interpreting the data and identifying the core findings, themes, variations, and relationships in and between the themes was a continuous one. Once all texts were organized, this process involved moving back and forth between the coded data, the analytic notes, and relevant theoretical and empirical literature. In the discussion of the findings, Svenaeus' (63) phenomenological theory of health and illness and the concept of unhomelikeness provided a theoretical understanding of the meaning of being a patient with IBS in the encounters with health care.

In *study IV*, the analysis proceeded according to the following steps: First, the interviews were listened to, and the transcriptions were read several times to get a sense of the whole. Then each text was broadly organized to grasp the topics (e.g. descriptions about being in a group with others). During this process of organizing the data, analytical questions, comments, and possible premature interpretations were written down. The process of interpreting data and identifying patterns and their inherent variations, and how they were related, involved moving back and forth between the data, the analytical notes, and relevant theoretical and empirical literature. Other researchers' related empirical work supported the interpretations, whereas theoretical reasoning enhanced the understanding of the findings.

Because the strength and nature of focus groups are the interaction and exchanging of views and experiences between the participants, the analysis of data should also include the dynamics and argumentation within the group (96, 100).

In the process of identifying patterns and their inherent variations, the participants' ways of talking about the issues of interest were identified. Questions that were asked during this process included: Did the participants seem to defend their positions? Were they supportive of others? Did some participants dominate the discussions? Did participants exchange views, or did they avoid topics? This allowed disclosure of agreements, disagreements, and statements that encompassed the range of patterns within the findings.

For the purpose of ensuring rigor in both study II and study IV, verification strategies were built into the entire research process, through the main researcher's (CH) continuous theoretical and empirical knowledge development, and through guidance by senior researchers on issues concerning sampling, data collection, and choice of analytical method and theoretical perspective (101). The findings were repeatedly critically discussed with, and validated by, co-authors and research colleagues.

Additionally, in the case of study IV, the emphasis on interaction gave the focus group method a level of face validity, because what participants said during the group discussions, could be confirmed, reinforced, or contradicted (98).

Study II	Study IV
Listening to and reading original text to get a sense of the whole	Listening to and reading original text to get a sense of the whole
Writing of memos and broad coding of data into thematic groups, using NVivo	Writing of memos and sorting of data into groups by content
<p>Analytical questioning and interpretation of findings</p> <p>Moving back and forth between data and theoretical and empirical texts to support interpretation</p>	<p>Analytical questioning and interpretation of findings</p> <p>Identification of agreements, disagreements, moods, and ways of talking about subjects, within the focus groups</p> <p>Moving back and forth between data and theoretical and empirical texts to support interpretation</p>
Identification of themes, their inherent variations, and relationships among them	Identification of patterns, their inherent variations, and relationships among them

Figure 4. Illustration of analytical processes in studies II and IV

Study III

In study III, comparisons were made between the initial and the follow-up assessments. Statistical procedures were carried out using version 8.0 of the Statistica software package. The results from the IBS-SSS are considered to be of ordinal data type, and therefore non-parametric statistical methods (median, inter quartile range (IQR), Wilcoxon's signed rank test) were used for analysis (102). WCQ scores were calculated according to the manual (89) and analyzed with parametric statistical methods (mean, T-test for dependent samples) (102). Significance of differences was set at the 5% level ($p \leq 0.05$). Spearman's rank order correlation (102) was used to analyze possible associations between age, gender, and time and the results of the follow-up measures. The findings were repeatedly critically discussed with, and validated by, co-authors and research colleagues. Additionally, a professional statistician was consulted for advice about the choice of statistical methods and interpretation of data.

ETHICAL CONSIDERATIONS

This thesis is built mainly upon research data collected with qualitative individual or group-based face to face interviews. Interviews on matters that might be associated with strong emotions for individual participants can result in ethical conflicts between the knowledge desired by the researcher and the possible harm to the interviewee. Providing oral and written information regarding the study and its purposes, as well as forms of data maintenance and presentation to potential subjects, and emphasizing the voluntary aspect of participation, gives some protection against this (103).

The processes of recruiting participants and collecting data for the four studies were guided by the principles of autonomy and informed consent, as described by Beauchamp and Childress (104). These principles were maintained in the following ways: In studies I and II, an independent research nurse invited the participants by telephone, in order to protect the individuals from feeling awkward about declining to participate in the study if they wished to. Those who were interested in participating were sent written information about the study and a form to give written consent. At the time of inclusion, and again at the time of interview, each person was informed orally about the right to withdraw from the study at any time without having to present a reason. This was also included in the written information. The participants were informed that all personal particulars would be removed from the data during the process of transcription.

The interview method used in study I (open-ended) and also for the most part in study II, promoted free choice on the part of the participants as to what to talk about in the interviews. If the researcher reveals himself or herself as being genuinely interested in what the interviewees have to say, the interview might become an affirmative dialogue which is actually beneficial to the subjects, by allowing them to share personal experiences of living with an illness. Because the aim was to increase previously limited knowledge of what it is like to live with IBS and to be in the patient position in health care encounters, from the perspective of the patients, the benefits were considered to outbalance the potential risk of harm to the participants. The participants were also informed about the possibility of later contacting the IBS team at the hospital where the interviews were conducted, if they wished to talk about matters that had been brought up during the interviews.

In studies III and IV, the initial invitations to participate and the reminders were sent as letters, rather than being done over the telephone, to protect the individuals even further from feeling awkward about declining to participate if they so wished. In study III, the method chosen for data collection (questionnaires) promoted free choice on the part of the participants about what to answer. Similarly, the thematic broad questions used for the focus groups in study IV gave the participants free choice as to what to talk about. Still, there is always a risk that members of a focus group will feel hesitant to speak their minds if they feel that what they say is going to be spread around by other members of the group. In this study, the moderator guaranteed confidentiality on behalf of the researchers, orally and in writing. It was also suggested to the members of the group that they should make an agreement with each other not to mention details such as names when talking about the focus group interview with their friends and family. Finally, the participants were informed about the option to use an alias during the interview if they wished to, and assured them that all personal particulars would be removed from the data during the process of transcription (103). In addition to these precautions for minimizing harm, it should also be noted that participation in focus

group interviews can be of benefit to the participating individuals. In one study where focus group interviews were conducted to develop a self-help guidebook for people with IBS, the participants considered meeting others and sharing illness experiences during the study to have been a positive and therapeutic experience (35).

Approval to conduct the studies was granted by the local research ethics committee at Karolinska Institutet, Stockholm, Sweden.

FINDINGS

STUDY I

In the findings of study I, six interrelated key constituents were identified: having an altered self-image, feeling ashamed, distrusting the body, feeling tired, blaming one-self, and finding solutions. These key constituents were synthesized into the following structure describing the phenomenon: *Living with IBS means struggling with an unfamiliar and unreliable body. Tiredness, distrust, and feelings of shame towards the body bring about limitations in everyday life. At the same time, living with IBS means having a strong will to exceed the limitations and become familiar with one-self.*

Having an altered self-image

One expression of having an altered self- image among the persons in this study was their experiences of feeling bodily or mentally different from others and in relation to their prior self-image. They experienced a great deal of anger and frustration due to not being like everybody else, and feeling constrained by the illness and therefore unable to do social things like everybody else. The part of their body that was no longer functioning in a familiar way was seen as something separate; that is, the participants spoke about their abdomen as a diseased object set apart from their healthy selves. The participants' experiences of illness also affected their images of themselves as women and men. While the male participants expressed a sense of inner weakness and a loss of confidence, which they could not relate to masculinity, the women expressed concerns about their femininity that were related to the external appearance of bodily symptoms like bloating, and to not feeling attractive.

Feeling ashamed

The study participants described the bodily expressions of IBS as negative and sometimes taboo, making them feeling ashamed in relation to others. Living in a relationship and sharing everyday life with a partner was troublesome, especially in relation to intimacy and sexual activity; the bodily symptoms resulted in their having trouble feeling fresh and attractive, which brought about uneasiness and embarrassment. Those who did not have partners expressed concerns about becoming involved with another person, for the same reasons.

Not being able to trust the body, and fearing that undesirable bodily expressions might occur during social activities, at work, or in intimate situations, was described as bringing about feelings of being limited or constrained in everyday life.

Distrusting the body

Distrusting the body meant that everyday activities had to be planned in detail to prevent troublesome situations. For example, knowing the location of the nearest toilet was crucial for taking part in social activities. Some participants described how even the anticipation of trouble was enough to bring about feelings of being limited in taking part in social and other activities. Among the younger participants who had yet to start a family, the feeling of being constrained by the unreliable body also gave rise to concerns about not being able to manage parenting in the future, because of ill health.

Blaming one-self

The study participants spoke about blaming themselves for having aggravated illness by engaging in certain behaviours, for example, by being careless about their eating habits or having too much stress in everyday life. Some also blamed themselves in relation to having created difficulties for their partners, and expressed concern that their ill-health would destroy their relationships, since they felt that their illness often took up too much space in the relationship. Another source of self-blame was described by those participants who had children, and found that their illness affected their parenting. Specifically, they felt that irritation and conflicts between child and parent were an expression of the parent's diminished tolerance resulting from ill-health.

Feeling tired

Feeling tired was another prominent experience described by the participants. This was manifested as feelings of being bereft of energy, which limited both social relations and the desire to maintain one's activities. Some participants also said that they had an increased need for sleep and regular sleeping habits. Working life was also affected; tiredness and a reduced ability to handle stress or increased workload limited the possibility of advancement or assuming more responsibility at work. In addition, some of the participants felt that it was harder to achieve the same work results as they used to because of this constant tiredness.

Finding solutions

The participants in this study had a strong will towards finding solutions that would help them handle everyday life with illness. However, they did not feel that the information and self-care advice they received from health care providers was sufficient to facilitate this. Instead, they had tried to find solutions their own way, by seeking alternative care and sources of information, for example encountering homeopaths or going to public lectures about IBS. Another driving force to find solutions was that most of them found it hard to accept the identity of being a chronically ill person; strategies for avoiding this identity included refusing to go on sick-leave, or modifying their activities in everyday life. Overall, although they had been only moderately successful at finding ways to handle everyday life with illness, they all experienced satisfactory feelings of being less limited and more in control of their own lives when they managed to overcome difficult situations.

STUDY II

In study II, two oppositional core positions were revealed. The first position, experiencing unsupportive encounters, included three themes comprising a variety of experiences shaped by humiliation, insignificance, and abandonment. The second and less prominent core position, experiencing supportive encounters, can be viewed as an oppositional state. This position included one theme, being acknowledged as a person; this represented experiences shaped by mutuality, understanding, and acknowledgment of the person's lived experience of illness.

The study participants' descriptions contained experiences with various health care providers and professions. They all had experiences from primary care as well as specialist care settings and emergency care. In accordance with the way IBS health care is most commonly organized, there was an overemphasis on experiences of encounters

with physicians. However, the participants mostly described their experiences of encounters from an overall perspective of health care, and so the findings are presented with a focus on the meaning of the participants' experiences of encounters with health care as a context, rather than giving specific professions too much attention.

Experiencing unsupportive encounters

For the participants in this study, being in the patient position meant *being exposed to various faces of humiliation*. One typical experience was that of not being taken seriously. According to the participants, this was demonstrated by health care professionals who dismissed their illness experiences through the use of patronizing or ill-considered statements. They described having to struggle with their own experience of illness, as compared to the way they believed they were regarded by health care professionals. They described feeling accused of exaggerating or even imagining their illness, because there were no signs of disease, and therefore, they believed, their experiences were dismissed as irrelevant or nonexistent. They assumed that looking ill would have been beneficial, because they felt that visible proof of illness would have provided affirmation and legitimacy for help-seeking, and hence strengthened their positions in relation to the health care professionals. Symptom fluctuation, which is typical in IBS, was a common source of humiliation. The fact that symptoms could be obtrusively present on one day, and gone on the next, put them in awkward situations where they ended up justifying themselves to health care professionals, who they believed failed to take them seriously. Some of the participants had even felt the need to apologize for seeking help. Additionally, the study participants often took the blame for health care visits that turned out to be unhelpful because the body stayed silent. In this situation, when the body failed to provide evidence of the illness, they felt embarrassed and foolish and started to question their own illness experience.

All participants described situations in which they had not felt recognized as unique individuals, particularly in relation to medical investigation procedures or when they were being given advice about the disease. However, the foremost experience of *being insignificant as a person* was feeling as if their lived experience of illness was neither requested, nor of any significant value in the care situation. Lack of recognition was experienced by the informants as if their knowledge about their own bodies, health, and life situation neither mattered nor was utilized in the care provided to them.

The study participants believed that health care professionals regarded IBS patients as being of low priority because IBS was not a "real" disease. They also experienced a disinterest from the health care professionals in engaging with their illness once the medical inquiry was over. Little time had been made available to sit down for a dialogue, and in most cases the health care professionals had not initiated any follow-up visits or contacts. The participants did not feel that they were provided with enough information about the disease, the treatment options, or ways of managing the illness in everyday life. They described having to struggle to get attention of the health care professional, which led to feelings of being left with no acknowledgment or practical support to assist in the process of regaining health and wellbeing in everyday life; this was described as a feeling of *being abandoned* with nowhere to turn.

Experiencing supportive encounters

Being acknowledged as a person was the least-prominent theme in the findings of this study. One important issue of acknowledgment described by the study participants was

the mutual trust that could be facilitated in an encounter when the health care professional attentively listened to and engaged in the patient's experience of his or her illness and life situation. Feeling significant and being listened to promoted feelings of active participation in their own health care. Coming to a specialist clinic where the health care professionals had a high degree of knowledge and experience about IBS, including how the disease might influence everyday life, was described by some of the participants as a great relief. This was because there was an immediate recognition of the disease itself, as well as an openness and interest in trying to understand the meaning of being ill to the individual. In this environment, the participants felt that they no longer had to defend or justify themselves. Even though the diagnosis did not always help to increase the understanding of the disease and did not automatically provide wellbeing, it was still described as a confirmation of the participants' illness experiences. Accordingly, being acknowledged was also experienced as providing legitimacy through the diagnosis, especially in relation to health care providers.

STUDY III

In study III, the influence of the program was gauged by studying changes in coping patterns and symptom severity. The median time between the initial measure and the education program was 108 days (IQR 150), and the median time between the education program and the follow-up measure was 100 days (IQR 40). The relatively long interval between the initial measure and the education program was due to the waiting time and the individuals' own schedules; on several occasions, the participants had to reschedule their previously-booked education program week because of time constraints related to their work, study situation, or other commitments. Of the 51 participants, 40 completed both measures of the IBS-SSS, and 37 of these 40 also completed both measures of the WCQ.

According to the participants' self-assessments, the most frequently used coping strategies before the education program were seeking social support, escape-avoidance, and positive reappraisal. Conversely, the strategies scored as being most frequently used after the education program were distancing, self-controlling, and positive reappraisal.

Statistically significant changes in raw scores (mean frequency of efforts used on a specific strategy) were found for the two strategies of distancing, which was used more often after the education program, and escape-avoidance, which was used more seldom. Changes in the proportional use of total coping efforts (relative score values) were found in several coping strategies after the education program, but were only statistically significant in the case of self-controlling. Percentages of changes in relative scores are illustrated in table 5.

Table 5. Changes in the proportion of total coping efforts (relative score) used on a specific coping strategy before and after the patient education program (n= 37)

WCQ Coping strategies	Relative score at initial measure (%)	Relative score at follow up measure (%)
Confrontative coping	11.57	11.26
Distancing	7.84	9.67
Self-controlling	13.69*	16.36*
Seeking social support	13.67	12.76
Accepting responsibility	11.72	9.85
Escape-avoidance	12.77	10.81
Planful problem solving	17.02	16.60
Positive reappraisal	11.71	12.61

Note: *Statistically significant difference ($p \leq 0.05$) found for the coping strategy self-controlling ($p = 0.02$)

Among the participants in this study, the IBS-SSS overall score was significantly reduced ($p = 0.009$) after the patient education program. This reduction was also regarded to be a clinically noteworthy improvement (decrease ≥ 50), with a median difference of 57 (IQR 118/136) between the initial and follow-up measures. Within the individual questions, the participants reported a significantly lower experienced severity of bloating, dissatisfaction with bowel habits, and the overall influence of IBS on everyday life after the education program. However, there were no statistically significant or clinically noteworthy reductions in either number of days with pain, or pain severity (table 6). Among the extra-colonic symptom questions, severity of belching and/or passing wind, were scored significantly lower. A correlation analysis with Spearman's rank order correlation showed no associations between the scoring of symptom severity (initially or at follow-up) and age, gender, or response time (number of days between initial measure and education program and between education program and follow-up measure). Accordingly, symptom severity did not seem to be dependent on any of those variables.

Table 6. Differences in the participants' experiences of symptom severity, scored Before and after the patient education program (n = 40)

IBS-Severity Scoring System	Wilcoxon's signed rank test (p-value)
<i>Overall score</i>	<i>0.009*</i>
Number of days with pain within a 10-day period	0.151
Severity of pain	0.898
Severity of bloating	0.012*
Satisfaction with bowel habits	0.009*
Overall influence of IBS on everyday life	0.004*

Note: Significance accepted at $p \leq 0.05$

The study participants who had a clinically noteworthy improvement in symptom severity had the greatest changes in use of the coping strategies of distancing, self-controlling, and seeking social support. The change of coping patterns among these participants differed somewhat from that among those who scored a lesser improvement in symptom severity (table 7).

Table 7. Changes in the proportion of total coping efforts (relative score) used on a specific coping strategy, before- and after the education program, among participants with and without a clinically noteworthy improvement

	Confrontative coping	Distancing	Self - controlling	Seeking social support	Accepting responsibility	Escape-avoidance	Planful problem solving	Positive reappraisal
Participants with IBS -SSS								
Overall score improvement ≥ 50	+0.16%	+3.24%	+3.17%	-4.09%	-0.86%	-2.53%	+1.44%	-0.53%
Participants with IBS -SSS								
Improvement Overall score < 50	-0.15%	+0.63%	+2.33%	+0.79%	-2.47%	-2.19%	-1.45%	+2.52%

Note: A clinically noteworthy improvement (decrease of score ≥ 50) in IBS-SSS overall score was seen in 17 of the 37 who completed both initial and follow up measures of the WCQ. Relative score values are presented as percentage of increased (+) or decreased (-) proportional use of coping strategies.

STUDY IV

In the findings of study IV, four patterns (and inherent variations) emerged from the data: learning about one-self through others; being part of a community; understanding illness as part of a whole; and employing new strategies.

Learning about one-self through others

The pattern of learning about one-self through others can be viewed as a reciprocal activity of learning by listening to, telling, and observing others. The focus group (FG) participants described how listening to the stories of the other members of the education program had helped them to recognize their own illness and pattern of thoughts, feelings, and actions. They experienced this as having strengthened their self-images of being credible and trustworthy individuals.

The participants described how listening to the other program members had helped them put into perspective their previous feelings of helplessness, of self-pity, and of being a victim. This had enabled them to view their whole situation from a new angle. For example, not being the one who suffered the most was regarded to have been a significant experience. To hear that other members of the program had managed to overcome illness constraints in relation to social situations or at work was reassuring as it provided the FG participants with hope and inspiration for the future. Listening to the other group members' experiences of life situations could accordingly mean that the members of a group could become each other's role models in overcoming limitations in everyday life.

Most of the FG participants believed that the opportunity to tell others about their own illness experiences, along with the feedback they had been given, had helped them discover things about themselves that they had previously not been aware of. They also described how the strategies that they had already found useful in everyday life had been confirmed, and provided with meaning and understanding, when they were told to the other members of the education program. They experienced this as having a positive

effect on their self-trust. Similarly, when they had new ideas about ways of approaching illness that had evolved during the program, these could be confirmed or rejected by discussing them with the rest of the group.

During the FG discussions, some participants talked about learning experiences that occurred while observing other members of the education program. One example was linked to the practical exercises. Observing others fall asleep during a hypnosis session, despite previous claims of being unable to relax, was described as having provided a sense of confidence about being able to control illness.

For many of the FG participants, finding recognition and being given the opportunity to share experiences with others had provided acknowledgment and new perspectives. However, not all of them had been able to recognize their illness experiences among the other members of the education program. A few of the participants had felt that either they were alone in their symptoms, for example being the only ones in the group with frequent diarrhoea or faecal incontinence, or they were the ones who were the most troubled by the disease. For these participants, the burden of illness and of being different had become more obvious. They described this realization as having brought about feelings of sadness, but at the same time it brought a determination to learn more so as to enhance their readiness to make life-improving changes, and to seek additional health care support.

Being part of a community

Being among others with similar illness experiences was described by the FG participants as having created feelings of being part of a community. They described the education program as an environment which promoted feelings of ease and willingness to be open about one-self, and as a safe environment where they could speak out about matters related to their illness that were normally considered taboo or shameful.

The FG participants considered that the atmosphere of safety and openness during the education program had been supported by the facilitators' ability to maintain a relaxed approach towards sensitive matters. Another aspect mentioned was the issue of whether there were any topics that the participants considered difficult to talk about in a group setting like the education program. One such topic was intimate relationships and sexuality; a number of participants felt that the opportunity to talk about these had been missed. While some of them regarded this as too personal to talk about, others believed that because of the atmosphere of ease and the feeling of being given the free choice of deciding whether to be active or passive in the group discussions, it would not have been a problem if the facilitators had initiated the topic.

The mixture of sexes and ages in the program groups was also discussed but was not regarded to be of significant matter. In general, it was the mutuality in illness that was regarded to be the prime factor for the experience of being part of a community.

Most of the FG participants felt that being in a group with others who had similar illness experiences was a positive thing. However, others described experiences of feeling like outsiders in some situations during the education program. In these situations, when they had missed the acknowledgment of themselves as individuals, they considered the group to have been unsupportive, rather than bringing on feelings of intersubjectivity, because they felt different and not part of the community.

Understanding illness as part of a whole

During the FGs, the participants discussed their views about the origin of IBS and the relationship between the disease, their illness, and their life situation. Most of them said that after the education program, they had started to understand that their illness was an inseparable part of life as a whole. Understanding the interlinking between disease, illness, and life was described to have enhanced the participants' abilities to interpret bodily signals. This, they felt, enabled them to influence their own wellbeing by employing new and efficient strategies. Becoming aware of the intertwinement between thoughts, feelings, and actions made the FG participants feel increasingly able to alleviate symptoms such as abdominal pain and urgent bowel movements, as well as to master stressful situations in everyday life. A typical example was becoming aware of their breathing pattern, and the way their bodies responded to the breathing techniques they had learnt during practical exercises.

Understanding illness as part of a whole was described by most of the FG participants as having facilitated a growing readiness to improve their wellbeing. However, others talked about the difficulty of finding a balance in life, between being responsible on the one hand, and enjoying life and continuing their old habits on the other. They found it difficult to achieve a balance between the new knowledge about how to improve wellbeing, and what was possible to internalize in their everyday lives. Knowing what to do, but not being able to put this knowledge to use, could promote stressful feelings instead of being helpful. In this way, unexploited knowledge sometimes put new demands on the FG participants.

Employing new strategies

Many of the FG participants described themselves as people who took a lot of responsibility for others. This had previously often led to disadvantageous stress, frustration, and enhanced symptom severity. The education program had helped them reflect on the direction of their thoughts, energy, and priorities in life, which in turn had enabled them to start changing the focus of their efforts more towards themselves. They now expended less energy on the problems of other people such as friends, colleagues, or partners, and instead had started to care for and prioritize themselves. Giving precedence to their own wellbeing meant that they were becoming increasingly careful about their eating habits, taking time going to the gym, allowing themselves to do enjoyable things, or taking other preventive health measures.

The FG participants described how a mood of calmness had entered their lives since the education program. One issue that was discussed was the participants' previous tendency to catastrophize, which was linked to concerns about the disease as being dangerous or life threatening, and to fears of not being able to control troublesome and embarrassing symptoms. For many of the FG participants, this had changed after the education program. With their new knowledge about the disease, and their enhanced understanding of illness as part of a whole, they now viewed themselves as being capable of employing strategies that enabled them to approach the disease calmly and handle troublesome situations with a much more level-headed attitude.

Communicating their illness to people in the context of everyday life had also become easier after the education program. Understanding the connection between their illness and the underlying mechanisms of the disease had enhanced their ability to explain their own actions, needs, and limitations to other people. They described this new ability as having strengthened their position in relation to other people, because

they were now able to talk about the disease without fear of their knowledge being called into question. Additionally, they regarded their new knowledge as a door opener, facilitating more symmetrical relationships with health care professionals. However, some participants still viewed IBS as a difficult disease to explain to other people, and they continuously struggled to find ways of making their explanations comprehensible.

The FG participants said that making changes was not easy. New strategies often took a lot of effort to internalize, and situations involving meals could still be problematic. For many of them, the self-care advice about eating habits that they had been given during the education program not only contributed to illness improvements but also brought about stressful feelings, because of difficulties in putting the new strategies into practice. The degree of difficulty was related to the degree to which each participant felt able to influence their everyday circumstances. For example, working hours and lunch breaks were important factors, as was the extent to which the participants felt motivated to make the necessary investments of time and effort, in relation to the benefit of employing certain strategies. A few participants also felt that they needed additional individual support from health care providers, to help them sort out and transform their knowledge into applicable strategies to improve wellbeing in their everyday lives.

DISCUSSION

From a phenomenological point of view, the experience of the body is firmly interwoven with the nature of personhood and with the meaning of being a person. During the work presented in this thesis, it became clear that it was the experience of the body as unfamiliar and unreliable that challenged and limited the everyday lives of the study participants, both in relation to themselves and others. At the same time there was a strong desire to exceed the limitations. Another important finding was that the group-based patient education program endorsed the everyday lives of most of the participants. Following the program, the participants assessed their ways of coping differently, and reported being less troubled by their symptoms. The combination of reciprocal sharing of experiences and the provision of professional scientific knowledge together contributed to a growing readiness among the participants. This was based on new understandings of the body, of their illness as part of a whole, and of a new ability to make knowledge-based decisions about which strategies to employ. To summarize, the education program enabled the participants to enhance their wellbeing and find balance in their everyday lives.

The thesis consists of two parts; the first directed towards everyday life and health care encounters, and the second directed towards the patient education program. In the discussion, however, these parts will be discussed as interlinked.

The shamefulness of living with IBS

In study I, the participants described feeling ashamed of their bodies, both aesthetically and because of unpleasant bodily expressions, for example bloating or flatulence, often in relation to intimacy and sex life, sometimes leading to avoidance of such situations. Related findings, though conceptualized as embarrassing rather than shameful, have been reported in other studies (12, 17, 23, 37). Skarderud (105) makes a distinction between body shame and embodied shame. Body shame implies shame over body traits, for example the way we look; if we are skinny, tall, or have a big nose; and over matters connected with bodily functions, such as the symptoms brought about by IBS. Body shame is intimately connected to cultural values and ideals, and the shame is always related to interaction with others in a social context (105). Embodied shame, on the other hand, refers to an existential dimension of shame, implying internalized feelings of being ashamed of the self. This negative sense of self occurs when a person feels different from the way they want to be, in relation to the way they believe they are regarded by others (105).

In the modern western society, the body and some of our most fundamental bodily functions, such as flatulence and defecation, are considered to be private. This trend towards privacy began as early as the sixteenth century, and from the seventeenth century onwards there was an increasing development of shame and embarrassment as socially appropriate responses to certain bodily functions (106). This is well illustrated in Kubie's tacit schema of dirt, which he long ago claimed was embedded in the unconscious. This schema consists of a hierarchy organized on a dimension of cleanness and dirtiness, with tears being considered the cleanest bodily product, and faeces being considered the dirtiest. This schema has been tested in several research projects over the years, and been found to be "valid" in the sense that these values are still common among people in our society (107).

These values are also found in cultures outside the Western world, as exemplified in a study about the cultural bodily perspective of IBS among Taiwanese women. In this, the participants emphasized cleanliness, modesty, and reserve as being the expected social norms for women, and therefore the troubles related to IBS caused major embarrassment (37).

Lawler (107) claims that the civilizing processes has influenced the way the body is managed in society, and thereby also care practice. The tendency to make all bodily functions more intimate and private has created taboos around many things associated with the body. It is quite possible that these sociocultural norms and values influence the approach that health care professionals take towards people with IBS.

The experiences of being exposed to humiliation, insignificance, and abandonment in health care encounters (study II) seemed to add to the participants' down valuing of themselves. Encounters with health care professionals, according to Lazare (108), always involve potentially humiliating physical and psychological exposure. The patient is expected to reveal personal matters that are normally unspoken, to health care professionals who are often strangers, in unfamiliar health care environments. For people with IBS, this becomes a matter of having to reveal bodily issues that they experience as shameful. Such feelings were embedded in the descriptions of the participants in studies I and II. Shame in the context of IBS can accordingly be described as belonging to the embodied experience of unhomelikeness which was brought about by a negative evaluation of the self; a feeling that was enhanced in the participants' encounters with health care professionals (study II).

Schei (109) argues that shame represents a feeling of indignity. The health care professional thus needs to be careful about affirming a patient's shame in a caring encounter. Even though the intent is to acknowledge the experience of the patient and help the person to overcome the shame, it can actually be harmful in that it may instead confirm the shaming and self-devaluation that the person is struggling against. This in turn can add to the power imbalance in the encounter, putting the patient in an even more inferior position. In study IV, the participants described the ease and comfort they had felt in talking about taboos during the education program, saying that they experienced a feeling of ease in being able to talk about matters which were otherwise seen as shameful. This was brought about not only by the feeling of mutuality in illness among the group members, but also by the facilitators' downplayed approach towards introducing sensitive matters. Talking about sensitive matters might in view of these findings be easier and less shameful among people with mutual experiences, than in individual encounters with health care professionals. In individual encounters, health care professionals' understanding of the shamefulness of living with IBS, and their engagement in creating a trustful and intersubjective relationship with their patients become crucial for the preservation of the patients' dignity.

Different horizons of meaning in the encounters

Study II revealed that there was little intersubjectivity in the encounters between the participants and the health care professionals. One possible way of understanding this is as previously described by Toombs (110); the health care professional and the patient occupy different horizons of meaning in the encounter. The world of the health care professional is primarily one of disease, whereas the patient's world is one of lived illness. The two parties acquire two different types of knowledge that are both essential in the encounter. In study II, the participants' descriptions made it clear that there was no or very little acknowledgment of the patient's perspective during the encounters, as

the health care professionals did not invite the persons to share their experiences of illness. It is noticeable in these findings how the two different perspectives seemed to be incongruous rather than merging into some kind of shared understanding in the encounters, mostly to the benefit of the biomedical interpretation of the situation. Rejection of patients' expertise has previously been described in relation to other chronic diseases (29, 32, 111, 112), but only briefly in relation to IBS (12, 14).

Many of the descriptions of living with IBS among the participants in studies I and II were related to losses; of wholeness of one's life world, of self-trust, and of opportunities and freedom to live an everyday life without constraints. This may give the impression that the individuals were helpless and out of control. Rønnevig et al. (23) described their participants' expressions of reconciliation to struggle to be, in a sense, a way of "giving up" and accepting the situation. Conversely, the participants in this thesis demonstrated a strong desire to regain homelikeness despite the inherent challenges, and this desire was a driving force in seeking knowledge and support, and in making efforts to find ways to overcome their limitations. The strong will to regain homelikeness is linked to Jarvis' (72) ideas of disjuncture as being the fundamental driving force for learning and changing.

However, the participants in study II did not feel that they were being enabled to find ways to overcome their limitations in everyday life; they were given too little information to be able to manage their illness, and they were offered few chances to talk about the meaning of being ill. Their mood of unhomelikeness remained unnoticed by the health care professionals. They also experienced a lack of engagement and follow-up procedures, and this was described as an overall feeling of being abandoned by health care with nowhere to turn. These findings echo those from studies in other contexts, such as rheumatic disease (31) and fibromyalgia (32). Even though most of the participants in study IV agreed about the acknowledgment of the group members' perspective during the education program, there were those who similarly to the participants in study II felt abandoned, although here it was related to the time after participation in the program. These findings highlight the issue of organization of health care for people with IBS. Thorne (27) claims that much of the organization of health care for people with chronic illness is built upon the acute care model, where systems of diagnosis, referral, consultation, information access, and personnel resources are all predicted on the assumption that patient safety and system integrity depend on the expertise of the health care professionals. This kind of organization assumes that once a diagnosis has been confirmed and the patient has been informed and treated solely according to biomedical evidence-based practice, the patient is regarded to no longer be in need of health care. This model might be somewhat efficient in the acute care context, but considering the findings in this thesis, failing to take the life world experience into account seems to be counterproductive in the delivery of care for people with IBS.

The objective body of a person with IBS will always more or less continue to malfunction, but on the level of the life world, the unhomelikeness can be minimized and the balance in life can become less out of rhythm. According to Svenaeus (63), the goal of changing the present unhomelikeness of the patient's being in the world into something more homelike is dependent on the health care professional getting to know the patient's life situation. In this sense, there is a need for a mutual exchange of knowledge in the encounter. The health care professional has to learn from the patient in order to be able to use his or her expert knowledge in a way that is supportive of the patient's changed understanding of the situation. A relevant study here is one by James et al. (113), from the palliative care context, which revealed a rejection of the experiential knowledge of the patients' loved ones. The encounters which in study II

were experienced as being supportive were those characterized by respect and acknowledgment, and with an attunement that was trustful and appreciative of the life world of the individual. This was described as facilitating trust, comparable to the environmental characteristics of the patient education program (study IV).

The patient education program; a room for enablement

Studies III and IV both outline the significance of the patient education program. These findings call for some reflections regarding which elements of the education program were the key supportive ones for the participating persons and their everyday lives.

The education model at first appears to be rather traditional, in the sense that it is based on lectures given by specialists in various IBS-related areas. These lectures are followed by group discussions and occasional practical exercises. The program has a clear schematic structure. Accordingly, the program has the ambition of educating patients in matters that from the health care professionals' point of view are assumed to correspond to the knowledge needs of the participating persons. However study IV revealed another picture of the education program; as a room for enablement and mutual learning, allowing the study participants to improve wellbeing and regain a feeling of homelikeness in the body and in the world.

Being among others in similar situations was not only an opportunity to learn by sharing experiences; it also brought about feelings of mutuality and safety. The education program became a community in which the participating individuals were joined together by mutual illness experiences. Age and sex were not experienced as hindering the feeling of being part of this community. However, some participants said that they had felt excluded because their experiences of illness were different from those shared by the other group members. For example to be the only one in the group with constipation or faecal continence problems could bring about feelings of being unacknowledged and different.

Both the opportunity to share experiences and the professional knowledge provided by the facilitators of the education program were regarded as significant by the study participants. The importance of the provision of professional knowledge has been demonstrated in an article by Barlow et al. (114) on a lay-led self-management program for people with chronic muscular pain. Their participants said that they had missed the presence of health care professionals who could provide adequate information and explanations about disease and illness-related matters. Accordingly, it is reasonable to assume that both of these two horizons of knowledge, in combination with the environment of mutuality and safety, are important prerequisites in the education program, for the enablement of learning, and thereby the enhancement of wellbeing among people with IBS.

Another factor worth mentioning is the participants' appreciation of the presence of the nurse during the education program (study IV). They described the nurse as a health care professional with whom they could feel as if they were in a mutual relationship. This was because she was familiar from the introductory encounters before the education program. Additionally she was regarded to have a lot of experience and understanding about the circumstances of living with IBS. The participants' descriptions of the nurse correspond to one of Swanson's (43, 44) core concepts, "being with". This involves being emotionally present and attentively listening.

It is interesting to relate the findings from study IV, about the education program as a room for enablement, to those in study II. The participants in study II felt unseen and rejected as experienced persons in their health care encounters, and in most of these

encounters there was no mutuality between the study participants and the health care professionals. It seems that the patient education program has the potential to offer something which is not provided within the traditional health care system. Viewing the education program through the lens of Swanson's caring theory (43, 44), the education program seems to have been mostly successful in enabling the participants to feel capable and self-reflecting. The participants' natural desire to be connected with others was acknowledged through the group setting. As they were enabled to depart from their experiences of illness, they developed a readiness to improve their own wellbeing in everyday life.

Becoming more at home in the body

IBS is not a disease that occurs overnight. The participants in this thesis were not able to define a certain day or a certain time when their troubles started, but rather they identified periods in life "before and after IBS". Some of them said they had had abdominal problems for as long as they could remember, while others said they had been ill for a couple of years. Still, all of the participants in study I described the body as unfamiliar and unreliable; a body which they could not take for granted. From the way in which they spoke about their unhealthy abdomen as something separated from their healthy selves, it was obvious how the body was experienced as objective and intrusive. Following the ideas of Merleau-Ponty (65), the meaning structures were no longer helpful in giving meaning to the unfamiliar situations in which the participants found themselves. The attunement of experiencing the body as unfamiliar and unreliable can be viewed as a mood of unhomelikeness, as described by Svenaeus (63). From this perspective, the meaning of living with IBS for these people was a struggle with an everyday life that had gradually gone out of rhythm, as lived body had become unfamiliar and unreliable.

The concept of unhomelikeness might seem somewhat unfamiliar to health care disciplines because it is not a concept normally used within the language of clinical care practice. However, this phenomenological perspective of health and illness has important implications for care, as it clearly illuminates that living with IBS is not just a matter of having a problem such as an episode of diarrhoea or abdominal pain that needs to be resolved; rather, it colours the person's whole existence and understanding of the meaning of being a person in the world.

The body has been described as a source of creative expression of self; a way of expressing individuality and of experiencing personhood (107, 115). In study I, the participants' images of themselves were challenged by the disease, and there was a longing to be "normal" like others. The longing for a body which is just "there" and does not demand attention is related to the perceptions of what constitutes a good quality of life among the women interviewed by Bengtsson et al. (36). The longing for normality can be viewed as a desire to regain a mood of homelikeness in the world. The person quoted in the introduction to this thesis, illustrates how the disease had made him feel different and how he had started to become uncertain of his various roles in life, both in relation to himself and in interaction with others.

Another implication of the unfamiliar body was that it challenged the participants' (study I) feelings of femininity and masculinity. The women expressed feeling unattractive because of bodily symptoms such as bloating and flatulence. The men expressed less concern about their appearance, but more concern about a sense of inner weakness that influenced how they experienced themselves as men. These findings relate to the postmodern ideals of body, as well as the traditional roles of men as being

strong and in control (116). In our contemporary society, there is an increased focus on objectification, especially of women's bodies. In order to gain social approval, girls learn to practice self-surveillance early in life, watching themselves and judging themselves against prevailing social standards. This habitual self-monitoring often leads to body shame and dissatisfaction, according to Grogan (116). Charmaz (117, 118) provides an interesting perspective on the loss of self in chronic illness. She argues that many ill persons themselves hold the postmodern ideals about being independent and responsible for one-self, and that maintaining or regaining a normal life becomes the symbol of a valued self. Not being able to uphold this will ultimately call the person's own self-worth into question. It is worth taking this reasoning into consideration in relation to the findings in studies I, II, and IV. Many people with IBS are fairly young and still engaged in the process of finding out who they want to be as adults, partners, or parents. Hence, their loss of self in illness can be assumed to make the process of establishing a solid self even harder.

For the participants in study IV, the reciprocal activity of listening to, talking to, and observing others meant being able to learn things about themselves, and to view their own illness and life from a new perspective. The reciprocal sharing of experiences seems to have promoted the participants' self-esteem and decreased their feelings of being different. These findings agree with those reported in other chronic disease contexts (114, 119). Speaking about their own experiences was important, and the feedback from the other members of the education program helped them become aware of and understand their own ways of dealing with illness. Within narrative learning theory, as described by Hermansen (120), people's relations with the world are interpretative and create meaning. All narratives are about the self, and they also create the self. When the participants in the education program told their stories, and when they compared their own stories to those of the other group members, new meanings were created that gradually promoted their becoming more at home in the body and in the world. According to Bullington (70) it is our way of thinking about the mind-body-world poles that divides them, not our experience. Experiencing illness as part of a whole was a new perspective for the FG participants in study IV, because they were starting to think about themselves as "being" their bodies. Illness was no longer seen as something separate from the rest of their life, but was now starting to become part of their life world. Understanding illness as part of a whole facilitated a growing readiness among to improve their own wellbeing; but at the same time, they talked about the difficulty of achieving a balanced mood. Translated into the ideas of Svenaeus (63), achieving a balanced mood can be considered equivalent to regaining a homelike attunement in life.

Decreased influence of symptoms on everyday life

In the participants' self-assessments of symptom severity after their participation in the patient education program (study III), there were statistically significant improvements in the overall influence of IBS on everyday life, severity of bloating, and satisfaction with bowel habits. These findings are in line with previous work on multi-session educational interventions for people with IBS (56, 58). The changes in the assessments of coping patterns were greater among the study participants with clinically noteworthy improvements in symptom severity, in comparison to those with lesser symptom improvements. One possible interpretation of this is that the participants with the greater symptom improvements were more successful in finding and/or employing new strategies. Based on these findings and the findings in study IV, it seems reasonable to

assume that the self-assessments of decreased symptom severity after the education program were linked to the participants' experiences of having become more knowledgeable about the disease, and their changed use of coping strategies. However, life is embedded with complexity. In illness, a person's life world is most certainly coloured by his or her understanding about the disease, but also of other things that occur in life. Still, the findings of studies III and IV point to the assumption that the learning experiences gained during the education program, facilitated new knowledge that promoted changes in coping patterns, which increased the participants' capacity to practice self-care in their everyday lives. From the perspective of Merleau-Ponty (65), the education program can be described as having enabled the participants to regain their access to the world.

Regaining access to the world

The persons in studies I and II provide rather different descriptions about the way they experienced troubles and ways of dealing with illness in everyday life, compared to those in studies III and IV. It is important to point out that these studies are not methodologically designed for comparisons, but nevertheless the findings are interesting to reflect upon.

Not being able to trust the body, and the fear that undesirable bodily expressions might occur during social activities, at work, or in intimate situations, were described by the participants in study I to bring limitations in everyday life. Their access to the world had become restrained by their illness. These findings correspond to the more recently performed studies about the everyday life experience of IBS (16, 17, 23), although no one of those studies take their point of departure in life world and lived body.

One important implication of this was that close relationships were described to be affected. This was exemplified by the concerns that some of the persons had about starting a family. These concerns were related to a fear of being unable to take care of a child because of the troubles associated with IBS. The persons who already had children described feeling insufficient as parents. Especially at times when their symptoms were more severe and intrusive, they felt less tolerant and bereft of energy. Experiences of intolerance and even exhaustion among parents are certainly not unique for people with IBS. However, in this context, these experiences were described to be related to ill-health brought about by the disease. This aspect of living with IBS has not previously been paid attention in the literature. However, these are important everyday life experiences to recognize in providing support to people with IBS, as those who live with the disease are young and in the midst of being or becoming parents.

The participants in study III assessed their use of coping strategies differently after the education program. One significant change was the increased proportional use of the coping strategy self-controlling. In the findings of study IV it was revealed that enhanced knowledge about the disease had enabled the participants to handle troublesome symptoms with a more level-headed attitude. This can be viewed as a way of taking control of the situation.

The participants (study I) avoiding of situations because of the fear that something unpleasant might happen, is interesting in relation to the findings in study III. In these, the strategy escape-avoidance was assessed by the participants to be used significantly more seldom after the education program. One example of this was that the persons (study IV) no longer avoided communicating with people in their social context, about the disease. Another example was that they instead of avoiding putting themselves

in troublesome situations, used the breathing technique they had learnt in the education program, to take control of the situation.

Distancing was another strategy that the study participants had estimated a significantly increased use of, after the education program. The experience of having listened to the stories of other group members was described by the participants in study IV to have provided a new outlook on their own situation. For example they talked about realizing that others were more severely troubled, which made them no longer feeling sorry for themselves, and stop feeling like victims of their illness. This can in a way be interpreted as a way of distancing. It is reasonable to assume that enhanced understanding about the disease, both through the facilitation of scientific knowledge and the sharing of illness experiences, provided new perspectives and alternative ways of approaching illness.

The study participants' newfound abilities to employ strategies and to make changes through knowledge-based decisions had contributed to a growing readiness to improve their own wellbeing. This corresponds, not identically, but is linked, to Friberg's (26, 121) explication of the concept preparedness. Preparedness refers to feeling in control and being ready to act, and understanding the situation. The FG participants' new abilities and their growing readiness are considered to be applied knowledge, facilitated through learning experiences that occurred during their participation in the education program. As such this knowledge enabled the persons to regain access to the world.

The patient education program in empowerment perspective

Patient-centeredness, mutual acknowledgement, and relatedness are considered to be the main features of an empowering patient education (50). It has been proposed previously that the driving force for adult learning is motivation based upon experienced needs (73). Alternatively, as expressed by Jarvis (72), it is the desire to overcome disjuncture and return to a state of harmony. The findings of studies III and IV have raised the assumption that the patient education program made empowering contributions to most of the participating persons. However, for the few participants who were unable to recognize their illness experiences among those described by the other group members, the group and the exchange of information did not meet their needs. Hence, it can be argued that the education program was disempowering for these persons. On the other hand, the descriptions reveal that these persons had learning experiences during the program, even though they were not explicit as useful learning experiences to themselves, in the present situation. This is the kind of learning that has been described to happen pre-consciously (72). Nevertheless, it is relevant to raise the question of whether group-based education programs might be inappropriate for some people. It also points to the importance of balancing between the generality required for a group setting and the unique needs of each individual.

METHODOLOGICAL CONSIDERATIONS

Sample reflections

In qualitative research, optimal quality of data is ensured by an appropriate sampling of participants who sufficiently represent and have knowledge about the research topic of interest (85, 101). The participants in studies I and II had been troubled by IBS problems for more than three years, and had wide-ranging experiences of everyday life with IBS as well as of encounters within several different health care settings. Given that the

findings of these studies have helped to deepen our understanding of what it can be like for a person with IBS to live with the disease and to be in the patient position in encounters with health care, it seems that the sample size was appropriate in relation to the purpose of the studies and the methods chosen.

The participants in studies III and IV were recruited from the waiting list for the patient education program. As such, they were already acknowledged as being likely to benefit from participating in the program. This acknowledgement in itself might have influenced the attitude among the participants. All these persons had been admitted to specialist care, which might indicate that they were severely troubled by their IBS. However, Smith et al. (122) have shown that there is little or no difference in the severity of physical IBS symptoms between patients in primary and secondary care.

The number of men participating in all four studies was low. At the time of the studies, less than a fifth (14/87) of those on the waiting list were men, which is a lower proportion than in the IBS population in general (4). Hence, these studies provide only very limited information about gender differences in the findings.

The intention in study IV was to work with FGs of between five and eight people, as this number is large enough to provide a variety of perspectives, yet small enough not to become unmanageable (98). However, two FGs consisted of only two and three participants, respectively, because the remaining members did not turn up. Facing the methodological and ethical dilemma of what to do in such a situation, the decision was made to carry on with the interviews, since those who had invested their time in coming, wished to do so. These interviews turned out to be rich in terms of both information and interaction, and they were therefore included in the analysis.

Trustworthiness (studies I, II, and IV)

Study I used a descriptive phenomenological method. Due to the lack of previous research on the lived experience of IBS, the life world perspective of those who live with the disease was regarded as an important issue, informing further research related to health care. According to Giorgi (81, 82), verification of a phenomenological study does not entail trying to eliminate subjectivity, but rather clarifying the conditions under which human subjects actually gain valid knowledge. This means that it is the research process that should be verified, rather than the results themselves. Thorough, rich descriptions of the whole research procedure and, perhaps most importantly, of the analytical process, allow the reader to determine the quality of the study. In study I, the participants' descriptions were rich and detailed, yielding strong quotations, which facilitated the process of analysis. The transformation of meaning units into key constituents (figure 4) was repeatedly discussed with co-researchers. A reflection made, about the transformation of meaning units into key constituents is, that it is a challenging work to determine the difference between abstraction and interpretation.

The interpretive descriptive approach used in studies II and IV adheres to the general principles of evaluating the trustworthiness of a qualitative inquiry; epistemological integrity, representative credibility, analytic logic, and interpretive authority (85). However, Thorne (83, 85) argues that the positioning of the study in relation to moral defensibility, disciplinary relevance, pragmatic obligation, contextual awareness, and probable truth, requires verification strategies to be built in to the entire research process. The product of an interpretive description study should be knowledge pertaining to clinically derived phenomena, for the purpose of informing clinical reasoning and creating a sense-making structure for the variations that occurs in the reality of clinical health care (84, 85). Studies II and IV both had a clear focus on the

clinical context in which IBS care is performed, and as such, both studies are considered to have provided clinically relevant knowledge.

Interpretive description incorporates the idea of letting the nature of the data guide the choice of analytical approach rather than being forced into one specific method (85). The use here of this approach gave some insights worth mentioning. First, the inherent methodological freedom still demands that the methodology is situated in relation to other qualitative methods, and this in itself requires adequate knowledge about those various methods. There is also a challenge in judging the degree of interpretation in analyzing the data in a way that is consistent with the purpose of interpretive description. These matters were recently discussed by Hunt (123), who was also critical of the limited resources of instructive literature about the methodology. However, a guide to the interpretive description approach was published in 2008 (85), and proved helpful, particularly for the analysis of data in study IV.

In study IV, each FG interview included participants from different iterations of the education program. This means that some of the participants were known to each other, while others were not. Familiarity between FG participants can contribute to expanding the discussion, because it lets them relate each other's comments to previously shared experiences (95). It is possible that some of our FG participants felt awkward about either being familiar or being unfamiliar with other participants. This was however not explicit, and the participants all joined in the discussions, even though some were more talkative about the subjects than others. The impression of the interplay in the FGs was that the positive climate contributed to the provision of data that fulfilled the aim of the study.

There are divergent opinions about the extent to which the interaction should be in focus in the analysis of FG data. Morgan (124) argues that the research question should determine the importance of interaction. In this study, the focus of the interviews was primarily to capture the variations in the experiences of the FG participants, which emerged in their common exploration and expanding of the discussed topics of interest.

Researchers' pre-understanding

The main researcher (CH) of the studies in this thesis had a pre-understanding derived from having previously cared for people with IBS, and from scientific reading about previous empirical research in the specific area of interest and related fields, and theoretical perspectives linked to the research project. Two of the co-researchers (BM T & E SB) had many years of experience of researching the patient perspective within the field of caring science, though neither had any previous knowledge about IBS. The third co-researcher (HN) was a gastroenterologist who has performed medical research and worked in the clinical IBS context for many years. He was also the founder of the patient education program. According to Giorgi (81, 82), in phenomenological research, the researcher has to remain open to the phenomenon studied and put any assumptions and pre-understanding to the side. One could, like Dahlberg (60), argue that this is impossible and that it is more a question of being aware of and restraining the pre-understanding. In study I, efforts were made to use the latter approach, by maintaining openness during the research process. The pre-understanding and its possible influence on the data was continuously reflected upon and discussed with co-authors. In studies II and IV, an interpretive description approach was used. This differs from the descriptive phenomenological method in that the theoretical and practical knowledge that the researcher brings to the research project is acknowledged as a point of departure from which to orient the research design and new inquiries (85).

Another aspect is linked to the role of the researcher in relation to the data gathered. The main researcher (CH) is head of care development at the hospital where the research was performed. Although not being practically involved in the IBS care, this may have influenced the degree to which the study participants felt free to express their true opinions about their health care encounters and the education program.

Validity and reliability (study III)

Study III used an evaluative before-and-after research design without a control group. The decision not to use a control group was based on the difficulties of finding a comparable group of patients. Randomization of the patients on the waiting list to the education program was regarded to have been unethical, as most of them had already been waiting for a long time, and would buy the randomization risk having to wait additional time. Additionally, many of the patients on the waiting list at that time, were diagnosed by, and referred straight to the patient education program from external care givers.

The internal validity of an evaluative before-and-after design can never be guaranteed because there is always a risk that factors other than the education program may be responsible for any differences between the two measurements (87). In this study, there was a relatively long median time between the initial measure and the education program. Hence, there is the possibility that there might have been changes occurring in the individuals' illness profiles or life situation during that time, and this may have influenced the outcome. There was also a relatively high dropout at the follow-up measure, which may have influenced the overall result. On the other hand, the demographic profile of those who dropped out did not differ in any way from that of the participants who completed the follow-up questionnaires.

One of the questionnaires chosen, the IBS-SSS, is frequently used for measuring symptom severity. As mentioned in the discussion of the findings, it was used previously in a similar Swedish context of IBS patient education (125), showing similar findings to those in study III. The other questionnaire, the WCQ, has been used previously in its English version for measuring coping strategies among people with IBS (93, 126), but with divergent outcomes. The Swedish version has been used in only a few published studies (92, 127, 128), none of them within the IBS context, which must be considered a limitation of reliability.

In researching the patient education program, the aim was both to evaluate differences in the participants' wellbeing and ability to manage illness before and after the education program, and to achieve an understanding about the influence of the education program on their everyday lives as a whole. Therefore, both quantitative (study III) and qualitative (study IV) methods were chosen to complement each other and provide a broader knowledge perspective. The strength of study III is that the results build on the participants' self-assessments of coping and symptom severity. Improving people's abilities to cope with illness in everyday life is an important purpose of patient education programs, which has not previously been addressed in the literature about patient education and IBS.

CONCLUSION AND IMPLICATIONS

This thesis provides a patient perspective on everyday life, health care encounters, and patient education, in the context of IBS. In this, the experience of living with IBS has been shown to be dependent on the fluctuating nature of the condition and the socially unacceptable symptoms related to the disease. Among the profound experiences revealed were those of the body as unfamiliar and unreliable. This challenged the participants' self-image and brought about feelings of shame and of being limited in everyday life.

The nature and attunement of encounters between people with IBS and their health care professionals can influence the existential understanding of a person with IBS, and his or her experience of illness, in a way that either boosts or obstructs the feeling of homelikeness in life. The most common experiences were of unsupportive encounters, characterized by humiliation, insignificance, and abandonment.

The group-based patient education program that was the focus of studies III and IV improved the everyday lives of most of the participants. After the program they assessed their ways of coping differently, and reported being less troubled by the symptoms. The combination of reciprocal sharing of experiences and the provision of professional scientific knowledge together contributed to a growing readiness among the participants. This was based on new understandings of the body, of illness as part of a whole, and of a new ability to make knowledge-based decisions. Hence, the education program enabled the participants to enhance their wellbeing and find balance in their everyday lives. The education program can be described as an environment that facilitated recognition and sharing of illness experiences, and as a place characterized by safety and intersubjectivity. These were assumed to be important prerequisites for the participants in enabling them to learn to live with the disease. The findings point to a number of areas of relevance to consider in clinical IBS health care practice as well as future research:

- In IBS health care, the patient perspective needs to be acknowledged as equally important as the biomedical perspective. The patients' experience of illness needs to be the starting point in any encounter between patients and health care professionals. People with IBS need to be recognized as resourceful and experienced individuals with unique needs, and so health care professionals are to be viewed as consultants whose task is to enable their patients to become autonomous and self-supportive. Towards this goal, the organization and content of IBS health care deserves further attention.
- The shamefulness of living with IBS needs to be recognized, and efforts should be made to preserve each person's dignity in every health care encounter.
- In planning group-based patient education programs, careful consideration needs to be given to the balance between the generality required for a group setting and the unique needs of each individual. One way of acknowledging the individual is to be flexible in modifying the content of scientific knowledge from time to time, and in bringing together groups of people with similar illness profiles. This would diminish the risk that the participating individuals will feel unacknowledged.

- Individually-based alternatives to patient education programs for people with IBS need to be made available for those who do not wish to attend a group setting. Today, the Internet offers vast possibilities for alternative learning opportunities. Many of those who have IBS are young, and are used to exploiting technology for obtaining information and communicating with others. Online support groups, interactive education programs, and chat lists are some examples to consider for the future.
- To evaluate the sustainability of the positive influence that this education program has had on the lives of most of the participants, studies with a longer follow-up period would be useful. Studies comparing this education program to other models are also suggested. One interesting approach could be to evaluate educational interventions based on a life world perspective and/or related learning theories.
- This thesis does not provide an extensive gender perspective on the experience of living with IBS. This is suggested for future research.
- Finally, a reflection about the patient education program. Even if the number of patients attending the program each year is larger today than it was during the time of the studies, still it is available only to a small proportion of the total IBS population. Most people with IBS must find their support within the regular health care organization; and the availability of IBS-competent multi-professional resources vary between health care providers and regions. It is interesting to reflect on whether this education program in fact has the potential of being viewed as an IBS health care model, “wrapped up” and designed from the perspective of chronic illness, in a thoroughly considered package. If so, it could be implemented and systematically evaluated in a broader perspective. Another question is whether it is the health care system that needs to be the main organizer of patient education programs for people with IBS, or if this could be done in co-operation with patient organizations and educational associations.

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APPENDIX

WAYS OF COPING QUESTIONNAIRE (WCQ)

WAYS OF COPING QUESTIONNAIRE Frågeformulär om förmågan att hantera dagligt liv

Instruktioner

När du svarar på påståendena i frågeformuläret, tänk efter ett ögonblick på en situation som är svår eller besvärlig för dig. Situationen ska på något sätt vara förknippad med *Att leva med IBS i det dagliga livet*. När du ger ditt svar, håll den utvalda situationen i minnet. Frågeformuläret ska kunna passa in på många olika slags situationer. Försök att svara på varje fråga även om någon/några frågor kan verka "udda" utifrån din situation.

Läs varje påstående och ringa in någon av siffrorna 0, 1, 2 eller 3, till höger om respektive mening, för att markera det svarsalternativ som bäst stämmer in på dig.
Siffrornas betydelse:

- 0 = Stämmer **ej** in på min situation/**ej** tänkt eller reagerat så
- 1 = Stämmer in **lite grand** på min situation
- 2 = Stämmer in **ganska mycket** på min situation
- 3 = Stämmer in **helt** på min situation/tänkt eller reagerat så

Ange följande:

Civilstånd: Gift/sambo ☐ Separerad/franskild ☐
Ensamstående ☐ Änka/änkeman ☐

	Stämmer ej in på min situation	Stämmer in lite grand	Stämmer in ganska mycket	Stämmer helt in på min situation
1. Jag inriktade mig enbart på vad jag måste göra härnäst — på nästa steg.	0	1	2	3
2. Jag gjorde något som jag inte trodde skulle fungera, men jag kände åtminstone att jag gjorde något.	0	1	2	3
3. Jag försökte att få personen, vars ansvar det var, att ändra inställning.	0	1	2	3
4. Jag pratade med annan person för att ta reda på mer om situationen.	0	1	2	3
5. Jag kritiserade eller läxade upp mig själv.	0	1	2	3
6. Jag försökte undvika att "bränna mina skepp" och ansträngde mig för att behärska mina känslor.	0	1	2	3
7. Jag hoppades på ett mirakel.	0	1	2	3
8. Jag accepterade ödet; ibland har jag helt enkelt otur.	0	1	2	3
9. Jag fortsatte som om ingenting hade hänt.	0	1	2	3
10. Jag sov ovanligt mycket.	0	1	2	3
11. Jag riktade min ilska mot den/de som orsakat problemet.	0	1	2	3
12. Jag tillät mig att ta emot medkänsla och förståelse från andra.	0	1	2	3
13. Jag kände att jag ville göra något uppbyggande och positivt av problemet.	0	1	2	3
14. Jag försökte glömma alltsammans.	0	1	2	3
15. Jag förändrades eller utvecklades som människa.	0	1	2	3
16. Jag bad om ursäkt eller försökte gottgöra saken.	0	1	2	3

	Stämmer ej in på min situation	Stämmer in lite grand	Stämmer in ganska mycket	Stämmer helt in på min situation
17. Jag gjorde upp en plan för hur jag skulle gå tillväga och följde den.	0	1	2	3
18. Jag gav utlopp för mina känslor.	0	1	2	3
19. Jag insåg att jag själv hade orsakat problemet.	0	1	2	3
20. Jag drog viktig lärdom av mina erfarenheter.	0	1	2	3
21. Jag pratade med en person som kunde göra något påtagligt åt problemet.	0	1	2	3
22. Jag försökte få mig själv att må bättre genom att äta, dricka, röka, ta mediciner etc.	0	1	2	3
23. Jag försökte lösa problemet genom att chansa eller göra något som innebar en stor risk.	0	1	2	3
24. Jag försökte undvika att göra något förhastat eller impulsartat	0	1	2	3
25. Jag fick något nytt att tro på — en ny tillförsikt.	0	1	2	3
26. Jag fick en annan/djupare känsla för vad som är viktigt här i livet.	0	1	2	3
27. Jag gjorde vissa förändringar för att det skulle bli bra.	0	1	2	3
28. Jag undvek för det mesta att umgås med andra människor.	0	1	2	3
29. Jag lät det inte få påverka mig. Jag vågade tänka för mycket på det.	0	1	2	3
30. Jag rådgjorde med en släkting eller god vän som jag litade på.	0	1	2	3
31. Jag tog lätt på situationen; jag vågade att ta det för allvarligt.	0	1	2	3
32. Jag pratade med annan person om hur det kändes.	0	1	2	3

	Stämmer ej in på min situation	Stämmer in lite grand	Stämmer in ganska mycket	Stämmer helt in på min situation
33. Jag stod på mig och kämpade för det jag ville.	0	1	2	3
34. Jag lät det gå ut över andra.	0	1	2	3
35. Jag drog nytta av tidigare erfarenheter — jag har befunnit mig i en liknande situation förut.	0	1	2	3
36. Jag visste vad som måste göras och gjorde en extra ansträngning för att det skulle fungera.	0	1	2	3
37. Jag vågrade tro på att det hade hänt.	0	1	2	3
38. Jag lovade mig själv att det skulle bli annorlunda nästa gång.	0	1	2	3
39. Jag kom på ett par olika lösningar på problemet.	0	1	2	3
40. Jag försökte se till så att de känslor som problemet orsakade inte påverkade annat — problemet fick inte ta överhand.	0	1	2	3
41. Jag förändrade vissa saker hos mig själv.	0	1	2	3
42. Jag önskade att situationen aldrig inträffat eller var ur världen.	0	1	2	3
43. Jag hade fantasier och förhoppningar om hur saker skulle kunna utvecklas.	0	1	2	3
44. Jag gick igenom för mig själv vad jag skulle säga eller göra.	0	1	2	3
45. Jag tänkte på hur en person jag beundrar skulle gjort i situationen, och hade det som förebild.	0	1	2	3

Beskriv kortfattat den situation som Du tänkt på:

.....

.....

IBS SEVERITY SCORING SYSTEM (IBS-SSS)

Frågeformulär om symtomintensitet i samband med IBS

1a) Lider du av smärtor i magen? Ja ☐ Nej ☐

b) Om ja, hur svåra är dina smärtor?

0 ◆—————◆ 100
Ingen smärta *Mycket svåra smärtor*

c) Fyll i antalet dagar som du har smärtor under en 10-dagars period.

(Skriv antalet dagar som du har smärta ex. 1,2, 10). Skriver du 4 betyder det att du har smärta 4 dagar av 10 osv.)

Antal dagar med smärta _____

2 a) Lider du av buksvullnad? (*upplåsthet, svullen eller spänd mage*) Ja ☐ Nej ☐

b) Om ja, hur svår är din buksvullnad?

0 ◆—————◆ 100
Ingen buksvullnad *Mycket svår buksvullnad*

3) Hur nöjd är du med dina avföringsvanor?

0 ◆—————◆ 100
Mycket nöjd *Mycket missnöjd*

4) Hur mycket tycker du att din IBS påverkar eller inkräktar på ditt liv i stort?

0 ◆—————◆ 100
Inte alls *Totalt*

5) Lider du av följande:

a) Illamående eller kräkningar?

0 ♦—————♦100
Aldrig *Hela tiden*

b) Svårigheter att äta upp vid måltid?

0 ♦—————♦100
Aldrig *Hela tiden*

c) Huvudvärk?

0 ♦—————♦100
Aldrig *Hela tiden*

d) Ryggsmärta?

0 ♦—————♦100
Aldrig *Hela tiden*

e) Slöhet eller trötthet?

0 ♦—————♦100
Aldrig *Hela tiden*

f) Rapningar och/eller gasavgång?

0 ♦—————♦100
Aldrig *Hela tiden*

g) Halsbränna?

0 ♦—————♦100
Aldrig *Hela tiden*

h) Tåta eller brådiskande urinträningar?

0 ♦—————♦100
Aldrig *Hela tiden*

i) Lärsmärta?

0 ♦—————♦100
Aldrig *Hela tiden*

j) Värk och smärta i muskler och leder?

0 ♦—————♦100
Aldrig *Hela tiden*